

VULNERABILITY AND ABUSE: AN EXPLORATION OF VIEWS OF  
CARE STAFF WORKING WITH PEOPLE WHO HAVE LEARNING  
DISABILITIES

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## DECLARATION

I, the undersigned, declare that this thesis has been constructed entirely by me. The original work, of which this is a record, has not been accepted on any previous application for a degree and was done by me.

Signed .....

Date .....

## ABSTRACT

In recent years there has been increased focus on vulnerability and abuse however greater attention has been paid to this in relation to children, elders and in domestic situations. Within learning disability service there has been increasing attention on physical and sexual abuse as well as attention being given to abuse as it is perceived by people with learning disabilities.

The aim of this study was to explore the views of staff working within learning disability services regarding their views of vulnerability and abuse.

A phenomenological approach was adopted, as this is a subject about which little is known and the lived experiences of care staff and the meanings that they attach to them were being explored. Semi-structured interview was the chosen method for data collection. Twenty informants shared their views in this study. The data generated were themed and the findings were presented in two different but complementary styles: case studies and themes representative across the entire sample.

This research has highlighted a number of important issues. There is considerable difference in the meanings given to vulnerability by care staff and the range of meanings are further complicated when notions of risk are considered. A model is presented that illustrates experiences of vulnerability and confidence of the individual the impact of various experiences on those states. *For example* negative experience of bullying might increase vulnerability whilst positive family support might engender feelings of confidence.

The study showed that staff are more influenced by personal and family values than by policy. Though this study focused on adult protection policy it was evident that this also applied in the case of other policy.

The strong influence of personal values pervades all aspects of care. This was evident in the views of informants regarding abuse. Abuse is considered to range in severity from bullying, which is seen as prevalent but to an extent unpreventable, to sexual abuse which is considered by most to be taboo.

Neglect and infringement of rights were in the main not seen as abuse with both



being attributed to ignorance. Power, authority and/or control are felt to be essential in the management behaviour that challenges and is justified to that end.

In the context of adult protection a model for safety planning is proposed that shifts the emphasis away from risk avoidance toward an enabling person centred approach that recognises the importance to the individual of excitement in life that also may involve risk.

## ABBREVIATIONS

AMED	The Allied and Complementary Medicine Database
ASLIB	Directory of Information sources in the United Kingdom
BNI	British Nursing Index
CINAHL	Cumulative Index of Nursing and Allied Health Libraries
DOH	Department of Health
GREC	Grampian Research Ethics Committee
HMIC	Health Management Information Consortium
MSP	Member of the Scottish Parliament
MWC	Mental Welfare Commission for Scotland
NAS	Needs Assessment Schedule
NBS	National Board for Nursing and Midwifery in Scotland
NHS	National Health Service
NMC	Nursing and Midwifery Council
SAMHSA	Substance Abuse and Mental Health Services Administration
SWAP	South Wales Adult Protection
UK	United Kingdom
US	United States of America (Used in context of a document from USA)
VIA	Values into Action

Abbreviations used by respondents and presented as spoken within quotes

DLA	Disability Living Allowance
GP	General Practitioner
HIV	Human Immunodeficiency Virus
LD	Learning Disability
OK	Alright

## KEYWORDS

Vulnerability

Risk

Abuse

Values

Policy

Adult Protection

Learning Disability

Power

Control

Authority

## CHAPTER 1 INTRODUCTION

### 1.1 Background

This study is concerned with adult protection for those who have learning disabilities. In recent years policy has been developed for the protection of vulnerable people. Yet each policy uses its own language and is based on particular service views of vulnerability and abuse hence it may not adequately protect those it seeks to or perhaps it overprotects when the person deemed vulnerable has no say in the matter.

I have worked within NHS services for people with learning disabilities since 1983 and during that time have seen many changes in practice. Many practices of early days might be deemed abusive against present day culture and policy. An example of this is the manner in which staff managed challenging behaviour through the use of seclusion or denial of privileges. With the benefit of hindsight a diary of such events would have provided graphic detail of those practices but it is easy to be wise after the event.

My more recent experience of the topic has been from a management perspective investigating allegations of abuse. This was a traumatic experience for all concerned, including service users who had made the allegations, their peers, staff, management and people against whom the allegations had been made. Much has been learned from these experiences but there is a dearth of relevant research on this topic upon which to base best practice. In some instances allegations of abuse were made by student nurses and those disclosures were made after their placement had ended. This may be an indication that they would have been afraid to report their concerns during placement for fear of reprisals or a negative appraisal. This was also an observation of Carter (1999) when he conducted a study into why nurses abuse. Although in the United Kingdom we have a Public Interest Disclosure Act (1998) either people do not know of it or they do not have any faith in it.

Adult protection has begun to receive increasing attention over the last decade and the abuse of vulnerable people has been the subject of research studies however it has been disparate across the different care groups. A search of ASLIB (*accessed 28<sup>th</sup> July 2006*) using the search term 'abuse' revealed in excess of 800 research studies. By far, investigations into child abuse exceeded

that of other abused people. Of the non child related studies elder abuse and domestic abuse received considerable attention with mental health and learning disability receiving little attention. Of the few studies relating to learning disability the main focus was on sexual abuse. Despite the research focus on sexual abuse in particular it is difficult to attach any type of ranking to the different types of abuse since all abuse is harmful. Systematic bullying may be more damaging psychologically to people than a single act of frustration that is manifest in a physical assault *such as* a slap.

In 2000 the UK Parliament launched its guidance entitled 'No secrets: Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse' in which they proposed the development and implementation of multi-agency policies and procedures for protecting vulnerable adults.

Fundamental to this research is its focus on people with learning disabilities. Different models of disability impact on the way in which people care and support people and this is reviewed in Chapter 2.

## 1.2 Value base for present day learning disability services

Much of present day policy is underpinned by the theory of normalization and social role valorisation. According to Chisholm (1994 *pp 41*) normalization had its genesis in the 1960s although he credits Wolfensberger's development of the principles in the 1970s for what has been understood and practiced since the mid nineties.

Bannerman and Lindsay (1994 *pp 19 –20*) question if normalization is the 'Golden age' and they comment 'what is clear is that we cannot and must not try to understand our approach to these issues today in ignorance of what has gone before'. Churchill (1992 *pp 30*) suggests that normalization was only part of a strong movement towards putting the individual at the centre of the service rather than merely a recipient with that movement including empowerment and self advocacy. According to Malin (1997) a main argument against normalization is that the ideology is more significant than Wolfensberger seems to imply and he suggests there is also a need to address as a higher priority, those forces within society that disempower, devalue and categorize people. Walmsley (1997) questions if, as normalisation theory has it, the nature of learning disability is

rooted in normalisation. She argues that if this is so then that agenda would have people with learning disabilities taking part in society on equal terms with other citizens and that they must heroically rise above the impairment and join in a conspiracy to deny that their intellectual limitations matter. She goes on to pose 'Or maybe these limitations are not real, maybe they are socially created, and they can be undone'. She concludes that every form of disability gives rise to a particular set of restrictions on what the disabled person can do .... and even if they somehow rise above those limitations they will run the risk of being relabelled 'normal'.

### 1.3 Values and Attitudes

The attitudes held by staff and the values they hold greatly affect the way they serve the people they are employed to support. Smith and Brown (1992 *pp 90*) cautions that services, both old and new, operate with conflicting values where the idealised values to which they ascribe are belied by the ways in which they treat service users. Fitzsimmons and Barr (1997) draw on literature for a definition of attitudes and they conclude that, though definitions have both similar and differing views, they all acknowledge that an attitude involves a predisposition to think or act in a particular way in response to a specific stimulus. They draw a distinction between beliefs, values and attitudes that though interrelated are not interchangeable. Beliefs are non-evaluative knowledge about our world *such as* the cause of learning disability whilst values relate to an individuals sense of what is desirable, good, worthwhile and valuable. Values according to Fitzsimmons and Barr involve a judgement about the importance of beliefs held and guide our actions whilst beliefs and values combine to form attitudes.

Kitson (2001) draws a link between the attitudes held by people regarding those with learning disabilities having a right to have their allegations of abuse treated in the same dignified and respectful way as others in society and she writes of the low self esteem that those people often suffer when this does not turn out to be so. This low self-esteem she points out makes a person particularly vulnerable and the person may believe that to be treated in that way must be accepted. To wait until adulthood when attitudes and prejudices have been formed is too late she cautions. Rather, Kitson cautions, we should attempt to address those issues during school years when attitudes are not so ingrained and awareness of

disability can be raised.

Reinders<sup>1</sup> (2002) describes the ‘new vision’, where recent changes in health and social services have greatly influenced people’s lives with regard to social inclusion. The ‘new vision’ is one where the core values are self-determination, individual choice and rights of citizenship which he suggests betrays a commitment to the political currency of liberal society. But this author advises that the moral essence of community living is participating in other people’s lives and being accepted and appreciated by them – sharing one’s life with people. Reinders concludes,

‘I propose that this is the real challenge that people with intellectual disabilities pose for us, *i.e.* not so much what we can do for them, but whether or not we want to be with them. Ultimately, it is not citizenship, but friendship that matters’.

It is recognised that the values and attitudes of researchers and those being researched impact on the study. This is addressed in greater detail in Chapter 3

## 1.4 Study rationale

One of the reasons behind this study was that my work experiences led me to believe that there was no clear understanding of the terms vulnerability and abuse. The lack of understanding transcended the professional or service view and at times was contrary to the views of those it was intended to protect. Without a clear and commonly accepted view of the issue it was felt that the development and implementation of adult protection policies or legislation would be fraught with difficulty. This research has produced data that could be used to form the basis of a more cohesive and better understood policy for adult protection within services across the learning disability care spectrum.

The term *learning disability* was used throughout although I appreciate that in so doing I was guilty of labelling people. However I felt that this was necessary since the study did not include people in other care groups and the term was widely used in Grampian region where the study was conducted. Labelling and its effects are discussed in Chapter 2.

## 1.5 Aims and objectives

### 1.5.1 Aim

To conduct a detailed analysis of interpretations of the terms vulnerability and

abuse within learning disability services.

### 1.5.2 *Objectives*

- Carry out a review of the literature relating to abuse of vulnerable people and in particular adults who have learning disabilities
- Ascertain the views of staff relating to vulnerability and abuse through use of semi-structured interviews
- Clarify the range of meanings of the terminology used in relation to vulnerability and abuse

## 1.6 Synopsis of Chapters

This chapter has provided the background to the study. Values and attitudes are introduced in relation to present day service delivery as well as the impact of values and attitudes on the research. The rationale for the study is identified and the aim and objectives detailed.

This leads on to a review of literature relating to vulnerability and abuse within learning disability services (Chapter 2). In the first instance a historical perspective is presented and this illustrates why people with learning disabilities are held to have been disenfranchised. Key concepts within learning disability services such as power and empowerment and the advocacy movement are explored before reviewing abuse and vulnerability in greater detail.

The reviewed literature forms the basis for the study and from this the most appropriate method for the research is chosen (Chapter 3). Included here are details of the sampling, study design and data collection, handling and analysis. A presentation of issues relating to reliability and validity are considered as is the ever changing context of this study within Grampian.

In Chapter 4 ethical principles including consent, safety and security of data and ethical issues pertinent to this research study are the main focus. Detail of the application for ethical approval is included.

Results are presented in the form of five case studies with a final section presenting themes that draw upon the information provided by all informants. In this chapter the quotes of informants are shown in italics (Chapter 5).

A discussion of the research follows (Chapter 6). It is delivered under the broad headings: vulnerability, risk, abuse and power. The chapter considers the



meaning and understanding of the subject of this research given by informants. The contribution that these research findings make in providing a greater understanding of the meaning of vulnerability and abuse is presented. What the findings mean for practice is also discussed here. In particular vulnerability is presented as a dynamic concept in the form of a model. Safety planning is offered as an alternative to risk management. The results are considered in relation to other relevant research. The chapter concludes with reflections of the researcher and this section also details the strengths and limitations of the study.

The final chapter provides conclusions from the study and recommendations are presented.

## CHAPTER 2 LITERATURE REVIEW

### 2.1 Introduction

In this chapter narrative review of literature relating to abuse of vulnerable people is provided. The chapter begins with a review of abuse in general terms before going on to review the subject more specifically in relation to adults with learning disability.

A literature search of databases; BNI, CINAHL, AMED, ASLIB, HMIC and Medline produced a list of articles relating to abuse of people with learning disabilities with several focussing on sexual abuse *such as* Sequeira and Hollins (2003) - providing the first evidence from a controlled study that sexual abuse is associated with a higher incidence of psychiatric and behavioural disorder, and McCormack *et al* (2005) – a longitudinal large-scale study of sexual abuse in intellectual disability services. There was paucity of investigations into other types of abuse to which people with learning disabilities are subjected although Taylor and Dodd (2003) conducted research into knowledge and beliefs about abuse of vulnerable adults across Surrey. In this research they defined abuse in relation to a number of different care groups including those with learning disability. The Surrey research report presents findings across all care groups deemed vulnerable. The findings of that report related to learning disability showed:

- Staff within learning disability services were generally more aware of vulnerability and abuse than staff in other care services
- ‘There is a culture to accept service user to service user physical abuse’
- The group had a fairly good understanding of abuse types, with the exception of neglect.
- 86% of participants working in a learning disability setting would want some evidence of the abuse before reporting.
- 36% would be reluctant to report an allegation if they felt it was untrue
- 86% of participants stated they would report immediately. This was the highest rate 9 across agencies with the exception of the police.
- 50% would report abuse to a care manager.
- Most were conversant with policies for adult protection and a significant proportion had attended training

Their graphic representation shows 100% identified physical abuse 95% psychological abuse and 90% sexual abuse. Verbal abuse, financial abuse and abuse of rights were each identified by 65% of respondents but only 45% identified neglect. Taylor and Dodd were reassured that there was good awareness as to who can be a potential abuser. However, they highlighted that only 14% of participants working with people who have a learning disability mentioned that friends can abuse and 50% mentioned the risk from strangers. Additionally, more participants working in a learning disability setting mentioned other service users can abuse, although this was still only 57% of the group and this was illustrated with a qualitative comment similar to comments in this study.

In relation to reporting of abuse they found 86% of participants working in a learning disability setting would want some evidence of the abuse before reporting it and 36% would be reluctant to report an allegation if they felt it was untrue. In general terms they found that care staff within learning disability services were aware of adult protection policy and had attended relevant training.

Although there is increasing focus on adult protection much of the literature relates to elder abuse. *For example* Richardson et al (2002) reported on a randomized controlled trial looking at the effect of education on knowledge and management of elder abuse and child abuse *such as* was investigated by McLeod *et al* (2003) where the focus was on medical training to identify child abuse and neglect and a call by Eaton (2003) for shake up in the handling child abuse cases. Carter (1998 *ASLIB*) carried out a study into understanding reasons why nursing staff and care workers abuse patients and clients in their care. Taylor and Dodd (2002) reported their study and their focus was on all vulnerable people within care but was sub-divided into different care groups of which staff caring for people with learning disabilities comprised one group.

As well as searching databases, the review included relevant national and international legislation and policy which was accessed either in hard copy or through the relevant government websites.

In terms of written guidance for the investigation of abuse, much has been

developed based on literature relating to elder abuse (Brown, *et al* 1998a and 1998b). However since the year 2000 many regions in the United Kingdom have been developing their adult protection policies and publishing them on the web: in England (The Royal Borough of Kensington and Chelsea 2002), in Wales (Neath and Port Talbot Local Authority.) South Wales Adult Protection [SWAP] Forum (*accessed 19<sup>th</sup> September 2006*) the In Safe Hands Guidelines and Ireland (Northern Health and Social Services Board 2006) draws heavily on research and literature relating to elder abuse whilst in Scotland, the location for this study (Grampian 2006) the source of the information is less clearly defined.

## 2.2 History – evolution of learning disability services

In this section the evolution of learning disability services is considered. Parallel to this evolution there have been cultural changes in society. As services for people with learning disabilities have evolved their position in society has also changed. In segregated services in long stay institutions people with learning disabilities had little freedom of choice yet in the 21<sup>st</sup> century people are still marginalized and disenfranchised.

Labels associated with people who have learning disabilities have changed with the passing of time but the labels, however sensitive, have led to stigmatization. Labeling, stigmatization and marginalization are closely linked and these concepts are reviewed in greater detail later in the chapter. They are considered here relative to the desire in society to create a purer race which is grounded in the principles of eugenic theory as detailed by Sheerin (1998 *pp* 70 -73).

In order to put this research in context, it is necessary to look to history to examine the nature of services for people with learning disabilities and to reflect on how this has led to the disenfranchised position those people are in today. According to one of the UK's leading learning disability charities, Mencap<sup>1</sup> (*Accessed 6<sup>th</sup> December 2002*), people with learning disabilities were considered to be 'dangerous' and 'degenerate' at worst or at best public nuisances. Prior to the industrial revolution people tended to live in close-knit communities and literacy was less important than labouring skills hence people with mild learning disabilities could easily go unnoticed. Nevertheless, they go on to say that being viewed as the 'idiot', people with learning

disabilities were still subject to discrimination. The Poor Law was developed in 1834 and asylums were built to house people who were 'mad' or 'feeble-minded'. Within the culture of that time the development of asylums was the work of the radical free-thinkers. However as the numbers of people receiving care increased the standards deteriorated due to overcrowding.

The literature makes it clear that people who have learning disabilities have been marginalized throughout history and if not shunned or segregated then the general population has discriminated against them. Even at the end of the 90s Sheerin and Sines (1999 *pp* 39-49) reported that, despite Wolfensberger's philosophy of normalization, segregation was still evident even within community services. Yet today though they live in community settings, many people who have learning disabilities still live in isolation within those communities.

It is suggested by Smith and Brown (1992 *pp* 89 – 90) that institutions function in two ways – at a conscious level they function to care for people whilst at an unconscious level they serve to protect the public from people whom they perceive to be dangerous or pitiable and they describe the tensions between those functions. They assert that history shows how easily human services turn from benevolence to persecution and restriction. Even in 2006/07 public protection is on the agenda of the Scottish Executive in the form of Multi Agency Public Protection Arrangements (MAPPAs) and whilst it does not single out those with learning disabilities it relates to mentally disordered offenders (that might include people with learning disabilities) and makes special arrangements for their accommodations on release from prison

Beacock (1992 *p* 405), referring to early 20<sup>th</sup> century, cites the writings of Fernald [1912] when he indicates:

'They are an unutterable sorrow at home and are a menace and danger to the community. Feeble-minded women are almost invariably immoral, and if at large usually become carriers of venereal disease. Every feeble-minded person, especially this high-grade imbecile, is a potential criminal, needing only the proper environment in which to express such. The unrecognised imbecile is a most dangerous element in the community'.

As recently as the 1980s, Kekstadt and Primrose (1983) were advocating birth control using 'the pill' for women with learning disabilities whilst at the same

time suggesting that this measure did not increase promiscuity. Nevertheless they also considered sterilisation to be an option and in the event of pregnancy felt that therapeutic abortion could be considered. Clearly they had some sympathies with the eugenics movement. In an article in Learning Disability Practice reference is made to a report entitled *The right support: Report of the Task Force on Supporting Disabled Adults in their Parenting Role* in which it is suggested that many social care professionals assume that disabled parents need 'care' rather than support and that their children would be better off with a non-disabled parent (Anon 2003<sup>1</sup>).

Crosskill and Bano (1992 *pp.161*) referred to the involuntary sterilisation of women as:

an extreme example of the sexual violence that has been perpetrated against people with learning difficulties, ostensibly for the protection of society from the procreation of undesirable elements.

In his examination of social constructionism of knowledge about learning disability, Nunkoosing (2000) details the thinking behind this when he writes of eugenicism. He opined that contemporary sensibilities would see the congregation and segregation of men and women with learning disabilities as no longer tenable. However, according to him the eugenicists quest for production of fine offspring, its rhetoric and rationale are still being used to justify the death of unborn babies with disabilities. Because the disabled infant is presumed to be a burden, Nunkoosing suggests it is easy to attach a label that places the person in an 'outgroup'. Consequently he may be despised in society making it easier to accept the argument that such abortions will save both the baby and parents from future pain.

In her editorial article, Northway (2003) referred to a Radio Five Live documentary where screening for impairment, particularly Down's Syndrome, was being discussed. Northway reported that one contributor said the issue was not one of improving the number of 'good' babies. Rather it was a case of reducing the number of 'bad' babies. Northway echoes Nunkoosing's view that it is easier to think of termination if you attach a negative label.

Fitzsimmons and Barr (1997) report that in recent times there has been an increasing endorsement of eugenics attitudes amongst health care workers

towards people with learning disabilities although they point out that those attitudes were held more strongly by people who had less knowledge of, or contact with, people with learning disabilities.

Edwards (2002 *pp 182 – 183*) questions why it is thought that disability is a bad thing and he suggests that in order to assess this widely held view, an examination of the case for screening and termination on the grounds of disability is required. He concludes:

This area of inquiry is of great interest because the attempt to reduce the incidence of disability by screening or termination procedures ‘throws into relief’ so to speak our most prominent values .... such as autonomy, independence and the relief of suffering. However, it needs to be asked whether in reducing the incidence of disability one is actually acting in accordance with these values.

Moreover, Woodhouse (1997) draws attention to the later stage of parenting when women in particular who have learning disabilities are tested for their parenting skills often against their inadequacies rather than their skills and competence as parents and in many instances the children are removed. This, she argues, is against the trend for the general population where competence is assumed unless proved otherwise.

Crosskill and Bano (1992 *pp 164 - 165*) write of the efforts to protect people with learning disabilities from sexual abuse and exploitation through seven different Acts of Parliament which place sanctions on sexual behaviour. However, though they acknowledge the justification for protection, they point out that the impact of these laws is often an abuse of their human rights and a denial of their opportunity to give and receive love. Furthermore, it is worthy of note that the maximum prison sentence for someone found guilty of having sexual intercourse with a woman who is a ‘mental defective’ was just two years until recently when the Mental Health (Care and Treatment) (Scotland) 2003 increased that penalty.

Gates (1997a) describes this approach to creating the perfect race as negative eugenics, where means are adopted to decrease the number of ‘bad genes’, including segregation of people who have learning disabilities and birth control for women including sterilisation whilst positive eugenics is concerned *for example* with manipulation of genetic material and anti-natal screening to

improve the chance of good genes. Gates describes the latter as a more sanitized form of eugenics. Nevertheless, he points out that both approaches are 'direct evidence of society's inability to value people with learning disabilities'. Gates description of negative eugenics is worthy of further consideration since, as Woodhouse (1997) points out, the focus and follow-up of children born to learning disabled people has focused on women known to services whilst fathers with learning disabilities are virtually ignored. This raises a gender issue in relation to human rights and particularly to the right to found a family if negative eugenics might prevent women whilst men may continue to have sexual relationships that lead to pregnancy. It must therefore be asked 'Is it assumed in the case of learning disability that 'bad genes' are only carried by women?' or 'Do men who have learning disabilities only have sexual relationships with learning disabled women so that by targeting the women this will address the issue?'

Bannerman and Lindsay (1994 *pp 19 – 20*) question why we hold the attitudes we do of people who have learning disabilities and they suggest we are intolerant of the views held by earlier generations instead of recognising that where we are now is a product of a slow evolution of thought and attitude down through the generations. They remind us that that evolution is not ended. Spicker (2002) shares that view when he writes of chasing rainbows the end of which we will never reach. Thus it could be argued that, as the social construct of disability is contextual to its own time, place, and other influences that we are indeed on a continuum of understanding that could be likened to rainbow chasing. Nunkoosing (2000) suggests that much of what we know about learning disability is taken for granted. He provides examples:

- Degrees of learning disability can be measured as mild, moderate or severe
- Causes of intellectual impairment could be found in the genes, etc.

According to Nunkoosing 'this taken for granted knowledge allows us to postulate theories about people's thinking, problem solving behaviour and other constructed concepts such as self-esteem. Moreover, he suggests that meaning that is shared about learning disability is created through our language, social interaction and culture and is the product of specific contexts in professions such as health and social care.



## 2.3 Models of Disability

Disability is a construct of the social and economic structures of a society at a particular historical point whilst impairment is socially created and meaning is given to it through a variety of social practices (Chappell *et al* 2001 *pp* 45 - 50). They suggest that the social model distinguishes between impairment (i.e. the loss or lack of some functioning part of the body) and disability (i.e. the meaning society attaches to the presence of impairment) and that people with impairments are in fact disabled by a society that excludes, disadvantages and discriminates against them.

The social model of disability, they argue, can be contrasted with traditional ways of understanding disability which locate the problem of disability in the impaired individual and sees difficulties as the direct and inevitable consequences of impairment.

According to Thunem (1966 *pp* 47) disabled people are not one heterogeneous group. Disabled people are of both genders, across all age groups, races, etc and she questions what, therefore, they may have in common. In accordance with that she suggests that what disabled people do have in common, as different as they all are, is the problem of attitude. Using an example relating to physical disability, Thunem suggests that when a child is born with a disability the reactions of parents, family friends and neighbours may be of horror, sorrow, anxiety, bitterness, *etc* and the family are viewed as having been 'stricken' one and are regarded with pity. This view would be analogous to the occasion when a child is born with a learning disability. However in physical disability there can be perceived redeeming features as detailed by Ford (1966 *pp* 31). He recounted a personal experience in which he (who acknowledges a physical disability) was introduced by a friend as follows:

He's a cripple but he's quite intelligent.

Ford suggested that this was a veiled compliment in that in some way he was being described as an exception to the rule with regard to intelligence and that intelligence could be held to be a redeeming feature for one with a physical disability. Chappell *et al* (2001) however point out that evidence is available that indicates that some people with learning disabilities reject this view of

disability.

Models of disability provide a framework for understanding the way in which people with impairments experience disability. They also provide a reference for society as laws, regulations and structures are developed that impact on the lives of disabled people. There are two main models that have influenced modern thinking about disability: the medical model and the social model (Open University *accessed 24<sup>th</sup> September 2006*).

The medical model reflects the World Health Organization definition of disability and disabled people are seen as the problem. They need to change and adapt to circumstances (if they can), and there is no suggestion that society needs to change. In contrast the social model, developed by disabled people, is caused by the barriers that exist within society and the way society is organised. It is society that discriminates against people with impairments and excludes them from involvement and participation (Open University *accessed 24<sup>th</sup> September 2006*).

Goodley (2002) suggests that the disability movement favours the term disabled people to describe all people who are disabled by society and he states that when a label is owned, as the label learning disability is owned by the self advocacy group People First, groups are seen as separatist whilst disowning labels is viewed as the movements ignorance of the common experience of disabled people.

Defining disability, Richardson (1997) referred to the Disabled Peoples International movement that has fundamentally redefined the problem of disability from one of *deficits in the individual* to one of *barriers in the environment* from which definitions favoured by disabled people have emerged. Acknowledging disability as a social construct, created by the physical and social barriers evident in a world adapted solely for the non-disabled, he suggests this barrier model of disability emphasizes the potential for disability to be overcome by removal of such barriers.

However, according to Chappell *et al* (2001) Walmsley (1997) argued that normalization continues to influence the self-advocacy movement. In explaining the oppression of people with learning difficulties, she noted that

the self-advocacy movement tends to emphasize issues associated with negative labelling (drawing on normalization) rather than the consideration of disabling social and economic structures as set out by supporters of the social model.

## 2.4 Legislation

Since the outset of this study the Scottish Parliament has conducted a vulnerable adults consultation and introduced the Vulnerable Witnesses (Scotland) Act 2004. With the lead word in each case being 'vulnerable' there was immediately conveyed a notion of neediness however in the case of the most recent legislation the Adult Support and Protection (Scotland) Act 2007 there has been a more positive change of emphasis.

This placing of the adult at the forefront of the title is similar to the approach in the Adults with Incapacity (Scotland) Act 2000 and shifts the focus toward the adult and then toward the support required or measures to be taken with regard to protection or issues of capacity.

The NHS and Community Care Act (1990) has impacted the evolution of services. It came into being with the intent to resettle people who had lived in institutions for much of their lives into homes in the community. This provided opportunities for people to live in smaller family sized homes, however it was argued (Nally and Steele 1992 *pp* 54) that to just move the people into more domestic settings without a fundamental change in the value base would be tantamount to little more than a change of institution.

The Mental Health (Scotland) Act 1984 – Section 105 states that the ill treatment or neglect of people with mental disorder will be an offence. Sections 106 and 107 relate to offences of sexual abuse of women with learning disabilities, with section 107 specifically referring to male staff members only. However, in a review of the Mental Health (Scotland) Act 1984, the Millan Committee (Scottish Executive 2001) reported that section 105 appeared to be little used whilst sections 106 and 107 were criticized for criminalizing legitimate relationships while failing adequately to protect vulnerable adults. Despite that, 16 years passed since its enactment during which many people who could have been protected will have been subjected to abuse. In the new Act - The Mental Health (Care and Treatment)

(Scotland) Act 2003 Section 311 of the Act addresses non-consensual sexual acts with mentally disordered people and was not specific to females. In it a person is regarded as not consenting if he/she purports to consent as a result of:

- being placed in such a state of fear; or
- being subjected to any such
  - threat
  - intimidation
  - deceit
  - persuasion.

The maximum term of imprisonment for this offence is a life sentence which is a significant increase on the 2 years specified in the previous Act. In this new legislation recognition of legitimate relationships is made. However in Section 313 it is still an offence for persons providing care services to engage in sexual intercourse or any other sexual act with those for whom they are paid to support. The penalty for this conviction is imprisonment for a term not exceeding 2 years or a fine or both. This is similar to Section 107 of the old Act, with the only differences being that it now refers to sexual acts and is no longer limited to male carers. With this limited maximum term of imprisonment and always the potential that such acts may go unreported or undetected those who might intend to abuse may see this as an opportunity rather than a deterrent.

Section 315 refers more generally to 'ill-treatment and wilful neglect of mentally disordered person' and carries the same maximum term of imprisonment of 2 years for employed care staff who are convicted as the old Act.

Given that there are no statutory duties contained in the part of the Act relating to offences in which sections 311, 313 and 315 are contained best practice points have been highlighted which include the following:

- It would be expected that any response to concerns raised about the welfare of a mentally disordered person would be approached on a multi-agency basis, in line with locally agreed vulnerable adult protection guidelines and protocols.
- Local authorities, health boards and independent agencies commissioned by them, all aspire to working with persons with mental

disorder according to professional values and principles that ensure respect for individual autonomy and rights to self-determination. The pursuit of these aspirations would be expected to be balanced against these agencies' responsibilities to ensure that the person's rights to protection and the promotion of health and well being are also supported.

Scottish Executive (2004a *pp 81 - 84*)

Alarminglly Mencap reported that sex offenders target people with a learning disability because penalties are so much lower and this is a warning message for legislators (Mencap 2002<sup>2</sup>).

The Public Interest Disclosure Act (1998) does not address adult protection *per se* however it provides protection to individuals who make certain disclosures of information in the public interest; to allow such individuals to bring action in respect of victimisation; and for connected purposes where in the reasonable belief of the worker making the disclosure, certain conditions are met *for example* that they believe the health or safety of any individual has been, is being, or is likely to be endangered. This Act provides security for the individual making such a disclosure in regard to the disclosure.

The Human Rights Act (1998) gives legal effect in the UK to certain fundamental rights and freedoms contained in the European Convention on Human Rights. This Act means all public bodies must ensure that everything they do is compatible with Convention rights unless an Act of Parliament makes that impossible (The Lord Chancellor's Department 2002 *pp3*).

Of particular relevance to this research are the following rights and freedoms (underlined for emphasis):

*PROHIBITION OF TORTURE* (Article 3)

No one shall be subjected to torture or to inhuman or degrading treatment or punishment.

*RIGHT TO LIBERTY AND SECURITY* (Article 5)

No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law:

the lawful detention of persons for the prevention of the spreading of infectious diseases, of persons of unsound mind, alcoholics or drug addicts

or vagrants;

Everyone who is deprived of his liberty by arrest or detention shall be entitled to take proceedings by which the lawfulness of his detention shall be decided speedily by a court and his release ordered if the detention is not lawful.

Everyone who has been the victim of arrest or detention in contravention of the provisions of this Article shall have an enforceable right to compensation.

*RIGHT TO MARRY* (Article 12)

Men and women of marriageable age have the right to marry and to found a family, according to the national laws governing the exercise of this right.

*PROHIBITION OF DISCRIMINATION* (Article 14)

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

In their guidance entitled *Rights, Risks and Limits to Freedom The Mental Welfare Commission for Scotland [MWC] (2006)* state that staff need to consider the balance between their residents' self-determination and the duty to care. This document considers limits to freedom in the broadest context including use of physical and mechanical restraint and locking of doors but they do not give consideration to the use of seclusion. Although restraint is used by staff for the management of challenging behaviour (usually aggression) the MWC insist that it must never be used as a threat. This represents a shift in the thinking of the MWC who did not find such approaches acceptable in the late 1990s and early 2000s. Even on the issue of seclusion, the MWC for Scotland (2007) reticently acknowledge that in a few instances seclusion may be a 'last resort'. However, where it is suggested that detailed documentation in this regard is necessary they assert that seclusion should not feature in the care plan of any individual instead suggesting that it be included as a last resort in the service policies for use of restraint and/or limits to freedom. The MWC see the development of the guidance document as a paradox for the organisation since philosophically they do not agree with use of seclusion.

The Protection from Harassment Act 1997 may be a little known piece of legislation that might have served to protect people from harassment. In the section that relates to Scotland it is written:

Every individual has a right to be free from harassment and, accordingly, a person must not pursue a course of conduct which amounts to harassment of another and:

a) is intended to amount to harassment of that person on at least two occasions

*or*

b) occurs in circumstances where it would appear to a reasonable person that it would amount to harassment of that person

In describing 'conduct' the Act includes speech and 'harassment' includes causing the person alarm or distress. Penalties for harassment include imprisonment but despite this piece of protective legislation people with learning disabilities continue to be open to harassment. That the legislation relates to the person who is or may be the victim being the one to pursue civil proceedings implies that it is available to people who are able to articulate their feelings thus paradoxically it will fail to protect people who are amongst the most vulnerable in society.

Like the Protection from Harassment Act 1997, the Protection from Abuse (Scotland) Act 2001 requires that the person seeking protection from abuse is the one to make the application therefore it is of less benefit people with learning disabilities and particularly those with severe/profound disabilities.

## 2.5 Labelling and its effects, stigma and marginalisation

The notion that negative labelling leads to stigmatisation resulting in marginalisation which in turn attracts additional negative labels is a circular argument and it is difficult to consider each in complete isolation of the others therefore each is revisited as it has relevance throughout this section.

People First is an organisation concerned with self advocacy and one of their stated aims is 'To work towards doing away with labels which affect our lives in a bad way' (*accessed 11<sup>th</sup> August 2003*<sup>2</sup>). The Foundation for People with Learning Disabilities (*accessed 10<sup>th</sup> September 2006*) report that the first self-advocacy groups and the UK citizen advocacy movement began in the early

1980s and current citizen advocacy projects serve people with learning disabilities, as well as older people, people with mental health difficulties, children, and people with physical disabilities. Advocacy they say can help people state their case, influence decisions which affect them, obtain better services and be treated more equally. It can also protect people from abuse and neglect, redress the balance of power and help them exercise their rights and entitlements. However this will prove to be a considerable challenge for organisations supporting people in this quest since changing other people's attitudes can take many years. It is also worthy of note that even in 2006 Jingree *et al* (2006 pp 212–226) who studied interactions between staff members and people with learning disabilities in residents' meetings found that despite the tutors' best intentions, didactic patterns and non-response persisted and that because the participants with learning disabilities made no attempts to initiate discussion, tutors resorted to directing conversation and in this way the imbalance of power was reconstructed as a vicious circle. Walmsley (1997) indicates that People First's issue about labelling is due to their acceptance of the normalisation position that the labelling is the cause of the oppression.

In her discourse on the ideological elements of Wolfensberger's normalization theory Dalley (1992 pp 101) points to the dynamics underlying society's attitudes to devalued groups through the process of labelling and opines that people are devalued because they are labelled deviant. To emphasise this point she suggests that 'to be categorised as deviant may mean that such individuals are seen variably as menaces, subhuman, childlike, diseased, ridiculous'. Corbett (1995 pp 22) however suggests that equality and entitlement are much abused terms as, within 'special needs' services, they are usually qualified by 'if resources allow', 'when conditions are suitable' and 'where appropriate' and she draws on the work of Booth when she states that the challenge is made 'do we really consider a learner who gains Oxbridge entrance to be of no more value than someone who has learning disabilities?'

In his discussion on the social origins of normalization, Whitehead (1992 pp 49) suggests that the conservatism and paternalistic approach of the 1950s was overtaken by the work of Goffman who 'looked at labelling theory and in particular at how and why people were defined by others and explored the effect of this labelling process on people's subsequent behaviour'. Whitehead



suggested that labelling creates deviance or abnormality because the individual adjusts his or her behaviour to that ascribed to him/her by the label. However this can only have relevance with some labels *for instance* however unpalatable the label 'learning disability' might be for some, people so labelled would not then display behaviour to confirm that label.

Walmsley (1997), in setting the scene for her paper on *Including People with Learning Difficulties*, reports that whilst some academics were developing arguments that disabled people through their shared experience of social and physical barriers to full citizenship, are a distinctive social group, with common experiences of oppression the very different ideology of normalisation was developing in parallel. She points out that unlike the disability movement which was led by people with disability, normalisation was dominated by non-disabled people and was based on the tenet that people with learning disabilities deserved to have opportunities to enjoy normal patterns of life, the rhythms of the day and seasons, separation of work and play, an ordinary life, etc

Hughson and Brown (1992) suggest that consumers of services and those who support them are 'labelled individuals'. Hence it could be argued that for some reason or other every citizen carries labels thus the issue is less to do with labels and more to do with the purpose of those labels and how positively or otherwise they are used.

Gates (1997b) suggests that by being too politically correct in the terminology we use, and using the all-inclusive term learning disability to describe people across a spectrum of abilities, is perhaps to deny the specific needs of people with learning disabilities for specialist health and social care. He opines that there is need for a theory of disability grounded in the lived experience of those people and their carers that might result in better targeting of resources based on need.

In the same way that professionals fail to capture the important messages of people who have learning disabilities, People First, which is run and controlled by people with learning disabilities, may fail to capture the important messages of people who have profound and multiple disabilities who do not use conventional methods to communicate their views (People

First<sup>1</sup> accessed 11<sup>th</sup> August 2003). Nevertheless as a self advocacy group they offer important messages on labelling and its effects:

- We have learning difficulties
- In the past we used to be called labels like mentally handicapped, mentally retarded, intellectually handicapped or mentally subnormal
- We didn't like these labels as they kept us down. We choose to use 'learning difficulties' ourselves. It is a label which doesn't hurt us as much as those above
- Jars should be labelled not people!

'Self advocates have told us that they would prefer that we use the term 'people with learning difficulties'. We generally resist using this term. We have accepted the logic of the language of 'people first: we have mostly given up the phrase 'mental handicap' and have consequently taken up the new 'people with learning disability'. We bring in a range of knowledge/power discourse to justify our pretend deafness to the voice of self advocates. .... This is a discourse of domination because it suggests that others have the power to define people said to have learning disabilities, as they do not have the authority to name themselves' (Nunkoosing 2000).

According to Schriener and Scotch (2001) advocates of disabled people must face the issue that no matter what theory of equality and definitions of oppression are relied upon it must be recognized that the public and its political and legal establishments seldom enthusiastically embrace the idea of remedying inequities that exist in society.

Fitzsimmons and Barr (1997) suggest that attitudes are formed as a complex result of personal experience and through personally observing others interact. They suggest that attitudes are also influenced to some degree by knowledge gained through wider exposure to the media with its portrayal of people with learning disabilities. However, they caution that particular type of knowledge is not often tested for accuracy or truthfulness and consequently may be erroneous and biased. This would suggest that those attitudes are likely to be firmly held hence the changing of attitudes is likely to be very gradual. It may be that changing behaviour is more likely to be effective in the short term whilst continuing to address those deep rooted beliefs and values.

Fitzsimmons and Barr highlighted various points relating to people with learning disabilities gleaned from attitudinal surveys of health and social care

staff:

- In general hospitals they should be nursed in a side room and always be accompanied by a learning disability nurse
- Paediatricians have withheld or withdrawn treatment including hydration and oral feeding
- Where a condition has been potentially fatal but surgically correctable treatment has been withheld because a judgement has been made about quality of life or ability for independent living. This latter point it was felt was based on moral rather than clinical judgement.

Labels can be used positively in order to provide improved or specialist services to a particular group of citizens which excludes others from that service *for example* healthcare for women, diabetic clinics for those with diabetes and specialist services for people who have learning disabilities. However those same labels used to provide exclusive or specialist services can stigmatise and ostracise people if the label is not seen as a positive one.

In his article entitled 'A rose by any other name' Orme (2003) draws on William Shakespeare's observation that giving a rose another name would not diminish its intrinsic value. However, he suggests that giving a person a negative name *such as* defective does affect the way in which they are viewed by others including care staff and this creates a relationship based on dysfunctional power balance.

'Stigma is not just the use of the wrong word or action. Stigma is about disrespect. It is the use of negative labels to identify a person ..... Stigma is a barrier and discourages individuals and their families from getting the help they need due to the fear of being discriminated against'

(SAMHSA's National Mental Health Information Center *accessed 3<sup>rd</sup> January 2002*).

Corbett (1995 *pp 23 - 24*) proposes enthusiastically that there be an impetus to replace the language of stigma with the language of pride suggesting that a valuable tool in this transformation is the power of solidarity in peer support. This of course requires assertive behaviour. Whilst within the 'learning disability community' there are strong self advocates many would not be able to participate in any solidarity movement. Corbett states that the disability movement, like any radical political group, is reflective of minority views within the disabled community and will polarize opinions in its call to action.

In a discussion on the social construction of disability, Brown and Smith<sup>2</sup>

(1992 *pp* 173 - 174) argue that if normalization is to take the oppression of people with disabilities into the political arena it must clarify rather than obscure the conflicts of interest at the heart of services lest real liberation be jeopardised. Those conflicts might include people with learning disabilities passively accepting what is on offer and which fits with the much vaunted application of normalisation theory rather than stating his/her own preference that might seem contrary to that theory. Brown and Smith further suggest that stigma, prejudice and real disadvantage cannot be overcome by simply abolishing services and hoping that by acknowledging disability oppression will disappear. Furthermore, it is argued (Gates 1997b) that the quest for political correctness in terminology, (*i.e.* learning disability), may not – as is assumed – prevent stigmatisation. Smith and Brown (1992 *pp* 89) take this one step further by suggesting that frequent changes of terminology are an attempt at cosmetic change and they cite the work of Goffman when they suggest that stigmatised individuals may attempt to pass for normal rather than expose the painful fact of difference.

Stigmatization represents one end of the continuum of the process of assigning positive or negative labels to those we come across and then valuing or devaluing them as their labels warrant (Neuberg *et al* 2003 *pp* 31).

In defining stigma, Goffman (1963 *pp* 15 – 18) defines ‘an undesired differentness from what we anticipated’ and he describes it as a special relationship between attribute and stereotype. Goffman illustrates how stigma is sometimes concealed for a purpose *for example* in order to get into the army to fight for country but used later for the purpose of being released from the army when embittered with war. Whilst this is a compelling argument it is less likely that people who have learning disabilities would consider such a calculated measure. Nevertheless they are stigmatised by those who Goffman identifies as ‘normals’ – those who do not fit the category. Though stigmatisation is a potential for every person, all of humanity strive to avoid this undesirable state and the word stigma is never perceived positively.

Goffman (1963 *pp* 27 – 28) describes the situation where the discredited person’s failings can be perceived by ‘normals’ and that, in being so exposed, the stigmatised person can be displeased when those normals strike up a conversation or offer help when neither are sought. It would however be

wrong to assume that people with learning disabilities feel this way, or indeed that they do not without further research. Nevertheless the stigma of disability is ever present – no-one would ever seek it. Neuberg *et al* (2003 *pp*32) argue that as a social process, the human practice of stigmatization of certain others is rooted primarily in the biologically based need to live in effective groups.

In discussing group alignment and ego identity Goffman (1963 *pp* 137) writes of peoples' place in the social structure based on being a member of 'real' groups and 'not real' groups with the former being aggregates of individuals who suffer the same deprivations resultant from having the stigma whilst the latter is all other categories of which the individual may have association but those take secondary prominence to the 'real' group.

According to Goffman (1963 *pp* 138 - 139) professionals who take an 'in-group' standpoint may advocate a militant and chauvinistic line and he questions why it should be the case that people from the category represent others within it. He suggests that they [people from the in-group] might make representation like any other fair-minded individual interested in improving the lot of the category as a whole. He opines that this might be because they are thought to 'know better' or that they are thought to be linked together into a community that should be supported by its members. However he cautions that if the political objective is to remove stigma, militant pursuance of this cause will further emphasise the stigma. Ideally therefore successful achievement of that objective should result in no need to further campaign as total inclusion as equal citizens would be achieved.

Neuberg *et al* (2003 *pp* 37) wrote of people within society who are considered to be non-contributors and in their discussion on stigmatizing those people, they hypothesise that there are two categories: those who violate the norm of reciprocity via theft and those who burden the group through no fault of their own *such as* disabled people. This overlooks the intrinsic value that each individual brings to the group preferring instead the knowledge or skills contribution.

Kelly (2002 *p*18), in describing the word iatrogenesis called for a word to describe the situation that he likened to this where support staff who proclaim to help people form relationships actually increase their isolation. Although

the term iatrogenesis had its origin in medicine it does however have broader application. Illich (1995 *pp 1652-1653*) who first used this term stated:

I coined the term in reference to a medical establishment ... whose symbolic effects included the shaping of people's beliefs and perceptions, needs and claims.

Stevens (2002) suggests that the terminology preferred by the individual disabled person should be established and all people involved in his/her support or care should use that terminology. He further suggests that when the medical profession use polite terms with the intention of saving embarrassment they are actually showing their own embarrassment which, according to him, is viewed by some disabled people as oppression. In Goffman's (1963 *pp 36*) work on stigma he wrote of individual and group/category stigma. He referred to recruitment to *category* suggesting that lobbying may be done by 'natives' or by someone 'from the other side'. He stated that people with learning disabilities [mental defectives] are generally represented by someone from the 'other side' and he suggests that a task of those representatives is to convince the public to use a softer social label. However, he acknowledged that when 'natives' represent a particular stigma a new career can emerge that can in time impact on the person's ability to represent.

User and carer involvement in service planning are features of present day public services. Views of people with learning disability are being sought and in some instances they become paid employees of organisations *such as* Mental Welfare Commissioners, NHS Quality Improvement Scotland inspectors, etc and likewise family carers who secure employment representing a particular category, in this case people with learning disability. They are able to draw on personal experience, their own lived experience, whilst attempting to represent that of others whose experience may well be different. However, being employees of an organisation may also impact on their ability frank in their views when they are in opposition to those of their employers.

Schriner and Scotch (2001) state that for over three decades disability rights activists have challenged exclusionary and stigmatising processes that constrain people with disabilities. They opine that all environmental barriers

to participation by people with disabilities may not be eliminated by a policy strategy that focuses on discrimination and fails to address the many forms of oppression that do not fall under legal definitions of discrimination. According to them, rights based approaches to tackling this issue are necessary but they suggest it could be augmented by the use of a human variation model where disability is defined as the systematic mismatch between physical and mental attributes of individuals and the present (but not potential) ability of social institutions to accommodate those attributes. Whilst their writings focus on overcoming oppression for disabled people in America those writings also have resonance in this country where many of the assertions made have equal relevance in our society.

Kassah (2000 *pp* 516) wrote an article entitled 'Terminology - from language to action' in which he critiques a paper by Devlieger regarding language use and cultural meaning in the United States of the terms handicap and disability. Kassah suggests that the two are one and the same phenomenon and he supports this by stating that when one is not handicapped, one is not disabled and when one is handicapped, one is disabled with the only difference being that one precedes the other. And he cautions even though Americans now adopt the use of the concept disability, the understanding of how the concept of disability contrasts with the concept handicap may continue to exist mostly in the mind of experts if semiotics remains in focus. He points out instead that it may have been useful to highlight why it is preferable to replace the so called negative term (handicap) with another word with a negative prefix 'dis' as is disabled.

In her book entitled 'Bad-mouthing: The Language of Special Needs', Corbett (1995 *pp* 2-3) draws on her experience as an educator in mainstream and special needs schooling. Even her introductory chapter is challenging and thought provoking when she explains her choice of cover: a picture of a teacher/student interaction from 1871 with the caption 'Teaching the Dumb to Speak'. Corbett asserts that despite the shift in learning programmes toward advocacy and empowerment over the intervening years special education is still essentially about teaching the dumb to speak at both a literal and a metaphorical level. And she opines that the power of language is overwhelming: none of us are immune to the force of verbal imagery.

In his discursive relating to constructing learning disability Nunkoosing (2000) writes of language as social action. He states:

It matters when we refer to people who depend on human services as either clients or consumers or tenants or patients because each of these words also constructs people as not us but 'them'. And when we consider people as 'them' then it is not difficult to do bad things to them because they are not like us. As we get discomfited by our consciousness about the language of difference that populates our discourse we will continue to change the language of learning disability.

Orme (2003) shares that view and he believes that with the changing terminology in recent decades there have been concomitant changes in care. He makes a poignant remark when he reminds the reader that terms *such as* low grade or high grade defective were used in the 1970s to further categorise people with learning disabilities but the nurses who used such terms not too long after that railed against the use of a grading structure within nursing. Nevertheless the people who used such terms in practice in that time did not do so out of malice.

Still (2001 *pp* 55 - 56) suggests that marginalization has an application to any movement, group or individual whose contributions have little impact on the centre or mainstream and that it involves a relative lack of power and influence. However he points out that a person or movement with no pretension to power cannot be marginalized so he claims it is not simply a lack of power. Gilbert *et al* (2005 *pp* 287 - 296) in exploring issues of fundamental importance to the citizenship of people with learning disabilities discuss their somewhat ambiguous relationship with the labour market. They link this to contradictory social positions where at the same time they can be worker, voluntary worker and object of charity leading to conflicts with paid work and the benefits system.

In a study conducted by Cambridge and McCarthy (2001) looking at best value in services from users perspectives the most able participants of the consultation groups were the ones most aware of the stigmas attached to disability, learning disability, etc. According to the authors, potential areas for intervention and support to cope with this perception and with some of the more explicit aspects of marginalisation and exclusion included: coping with



bullying and bad treatment, assertiveness, positive disability images, self-esteem work and identity work in women's and men's groups. Segregation, exclusion and marginalization all relate to the isolation or 'leaving out' of certain individuals from the mainstream of society.

## 2.6 Vulnerability

Vulnerability has its origin in the Latin word *vulnerabilis*, from *vulnerare* meaning 'to wound' (The Compact Oxford English Dictionary accessed 18<sup>th</sup> October 2006)

The definition of vulnerable offered by Oxford is '**adjective** exposed to being attacked or harmed'.

Cambridge Dictionaries Online (accessed 18<sup>th</sup> October 2006) also define vulnerable as an adjective however in contrast to the Oxford Dictionary definition of openness to harm Cambridge Dictionary refers more to possibility or potential as follows:

able to be easily physically, emotionally, or mentally hurt, influenced or attacked:.

Yet the example offered in support of this by Cambridge is inconsistent with the description in that it refers to feelings where the definition refers to potential openness to exposure.

I felt very vulnerable, standing there without any clothes on.

This example is more consistent with the definition offered by Oxford.

Vulnerable is defined as: 1) easily hurt or harmed physically or emotionally, 2) easily tempted, 3) (*often* **vulnerable to something or someone**) persuaded or unprotected against physical or verbal attack from them. (Chambers 21<sup>st</sup> Century Dictionary 2006). Collins Dictionary (1999) offers a similar interpretation but also includes 'exposed to attack or financially weak and likely to fail'. Yet it is in its interpretation in legislation and policy that it has relevance in this study as well as its interpretation in practice.

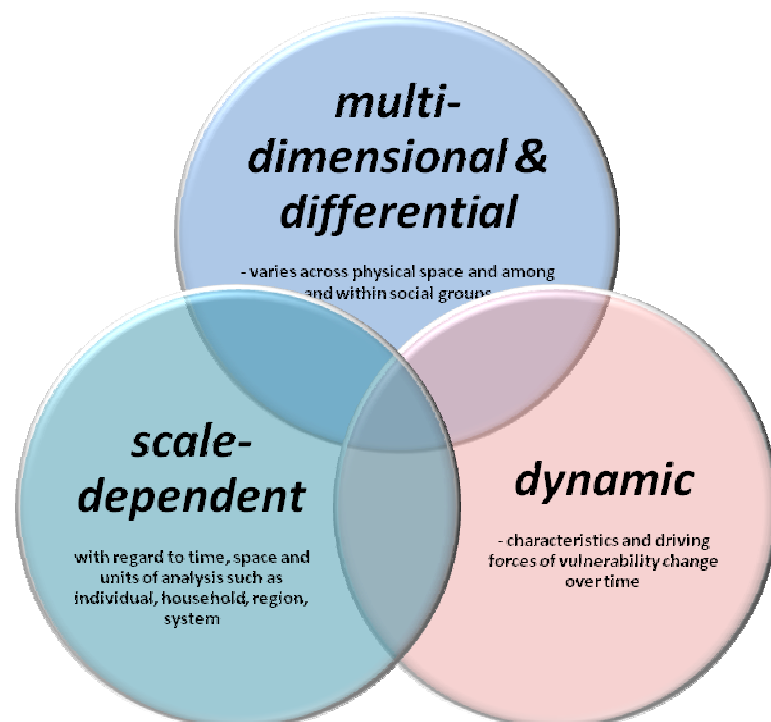
Clearly therefore there are many interpretations of vulnerability in relation to common usage of language however when considered in a specific social context there is greater need for clarity with regard to usage if it is intended to guide practice. Vulnerability has application in many very different social

contexts however there are common themes.

‘We are dealing with a paradox: we aim to measure vulnerability but we cannot define it precisely’. Those were banner headlines in a research brief of United Nations University (2005) focusing mainly on vulnerability to hazards of natural origin however contained within was analysis of vulnerability/susceptibility. Even though the focus of this research was natural disaster the defined concept of vulnerability has relevance to vulnerability in the context of care. Citing the work of Vogel and O’Brien, United Nations University point out that vulnerability is:

- multi-dimensional and differential (varies across physical space and among and within social groups)
- scale-dependent (with regard to time, space and units of analysis such as individual, household, region, system)
- dynamic (characteristics and driving forces of vulnerability change over time)

This concept of vulnerability can be conveyed graphically (Figure 1) to demonstrate the relationship between the three factors.



**Figure 1** Relationship between three factors of vulnerability

Approaches to measuring vulnerability should be simple, understandable and applicable to decision-making processes, such

as emergency planning and risk-reduction strategies

United Nations University (2005)

Also relating to natural disaster Yale University (2005) argue that the extent to which environments can be sustainable is dependent on how people and social systems are not vulnerable to environmental disturbances that affect basic human wellbeing and they suggest that becoming less vulnerable is a sign of a move toward greater sustainability.

Vulnerability is viewed from different perspectives. Legislative and policy documents invariably refer to vulnerability from a care perspective and in this context vulnerability means open to exposure to harm. Typically, though not exclusively the description is of people in receipt of care services and this of course requires that people are labelled; elderly, disabled, children, etc or just plain vulnerable although there is always a desire to add a label to emphasise the reasoning for the label. This definition might not include those exposed to domestic abuse and racial abuse.

The UK Government wished to improve the arrangements for dealing with incidents of adult abuse and so developed guidance to ensure that key local agencies - particularly but not solely health, social services and the police - were able to work together to protect vulnerable adults from abuse, by developing local multi-agency policies and procedures.

This document entitled 'No Secrets' used the following definition of the adjective vulnerable relating it to adults:

A vulnerable adult is a person: 'who is or may be in need of community care services by reason of mental or other disability, age or illness; and who is or may be unable to take care of him or herself, or unable to protect him or herself against significant harm or exploitation'

The National Assembly for Wales (2000) also used this definition. Whilst English and Welsh documents described vulnerability in terms of the individual, Scottish equivalents described it in terms of external factors. They defined the noun vulnerability as:

'the potential risks associated with physical and mental status of an individual which might reasonably be anticipated irrespective of the context in which care is provided'

However in the Adult Support and Protection (Scotland) Act 2007 there has been a shift away from using vulnerability as a descriptor toward use of the term 'at risk'. In this document 'adults at risk' are adults who 'are unable to safeguard their own well-being, property, rights or other interests, are at risk of harm, and because they are affected by disability, mental disorder, illness or physical or mental infirmity, are more vulnerable to being harmed than adults who are not so affected'.

With this shift from definitions of vulnerability therefore it is necessary also to define risk. In everyday usage, 'risk' is often used interchangeably with probability and implies a potential negative outcome at a future time.

In the United States of America, policy for adult protection has been developed in each State based on a definition in law. *For example* Washington State Department of Social and Health Services (*accessed 11/10/06*) state 'A vulnerable adult is defined by law as:

- a person 60 years of age or older who lacks the functional, physical, or mental ability to care for him or herself;
- an adult with a developmental disability;
- an adult with a legal guardian;
- an adult living in a long-term care facility;
- an adult living in their own or family's home receiving services from an agency or contracted individual provider; or
- an adult self-directing their care

Though reference is made to vulnerable adults in Australian legislation regarding adult protection, no clear definition of vulnerable is offered.

No policy that unambiguously delineates those who are not considered vulnerable has emerged though clearly some groups of society reject the label of vulnerability *for instance* battered women (Hansen and Stout 1996). Thus the focus is on inclusion in the criteria rather than exclusion. It is also worth considering that if, as claimed in Hansen and Stout's article, the vulnerability label is rejected by some then dealing with suspected abuse under vulnerable adult policies is fraught with difficulties since it must first be established

whether or not the person is vulnerable before further action can be taken.

### 2.6.1 *Vulnerability of disadvantaged groups within society*

Much has been written in recent years on the issue of vulnerability. *For example* Green (2001) wrote of vulnerable witnesses, pointing out that unlike the generality where adults are assumed to be competent witnesses, adults with learning disabilities are generally deemed incompetent in this regard until capacity is assessed and a judgement reached. Read and Elliott (2003) reported a vulnerability perspective on death and bereavement describing situations where people with learning disabilities often have to cope with this without being fully informed.

In a discussion about relationships between staff and service users, Smith and Brown (1992 *pp* 86) describe a situation where ‘individuals displace the violence which has been done to them onto others weaker than themselves’. They assert that when an individual has been enabled to acknowledge the hurtful or abusive incidents of their childhood they may be well placed to support service users who feel powerless or hurt. However they caution that people who remain unconscious of their own past traumas may use service users to replay their own humiliations. Clearly this must be a serious concern for employers within the care sector since some people who have been so damaged may see the care sector as a perfect opportunity for the individual to assume power over clients. This concern has relevance in all care groups since people in care often willingly surrender their power, thus rendering themselves vulnerable. Crowhurst (2000) writes of this as the dominator system and he argues that though we shut down the old institutions nothing has changed in that people using community services remain within the dominator system but he proposes a move toward partnership. This approach, he suggests, will challenge in a manner never before experienced in the history of Western civilisation.

### 2.6.2 *Vulnerability and Power Dynamics*

The influence of power is only implicit in the afore mentioned descriptions. This suggests vulnerability as being within the person whilst the Scottish Executive defines vulnerability in terms of risk. Mirow (2003) opens his discussion entitled ‘the power of vulnerability’ with a dictionary definition

similar to that above and he invites the reader to consider the implications of recognising one's own vulnerability. He suggests there are occasions when it is appropriate for professionals to share something of their own vulnerability and that that sharing can often lead to mutual respect.

Within care services vulnerability is a symptom of the power dynamics where care staff often assume positions of authority whilst people using services portray powerlessness. Randall (1997) suggests that little research has been done on the relationship between the use of aggression and the enjoyment of power but most people will have come across such situations where individuals or groups derive satisfaction from the harassment of someone else.

Vulnerability and power dynamics go hand in hand but it is useful to consider each separately before considering the effects of one on the other. In the context of abuse of vulnerable adults, vulnerability can be considered to be a social condition, since, for vulnerability to be possible there must be at least a second person. In cases of neglect, the absence of another may be the reason for neglect hence it can be assumed that neglect is only possible if another person by their acts or omissions can be blameworthy. Referring to a Home Office document [1998] entitled 'Speaking up for Justice' Clare and Murphy (2001) states that as for other groups who are socially disadvantaged and excluded, the vulnerability of people with learning disabilities is often based as much on the imbalance of power in relationships with others as in their individual characteristics.

According to Hansen and Stout (1996) not everyone who is assaulted, shouted or sworn at or even had their money or possessions stolen from them consider themselves vulnerable. This would suggest that vulnerability is in fact a condition that may or may not be accepted by people who are so defined by society. Must it therefore be the case that for a person to be deemed vulnerable, they must own the label? This would present difficulties for politicians and policy makers in that the development of adult protection policy is based on the premise that certain members of society are vulnerable because of the labels they carry *such as* learning disabled, elderly, homeless, *etc.* In many instances people neither own the care group label nor the vulnerable label but the former has an influence over the latter. It could further be argued that in instances where individuals do not perceive

themselves as vulnerable but labels attached to them place them in a vulnerable group, such moves are designed to protect the sensibilities of others in society.

Mirow (2003) suggests that a more positive view of vulnerability is that it enables us to be aware of danger and risk, to learn new and creative ways of being and to form meaningful relationships with people as we deal with our mutual needs. Nevertheless he acknowledges that most learning disabled people are not deemed by professionals as being trustworthy and, being vulnerable, need to be controlled and guided by experts who are portrayed as being wiser.

Despite all of the measures out in place through legislation and policy to protect vulnerable people living in care settings they are still open to abuse. It can take many forms including the widely accepted terms such as physical abuse, verbal abuse, psychological or emotional abuse, abuse of human rights as well as neglect and institutional abuse. The whole notion of vulnerability is worthy of consideration in this context. Though there are undoubtedly vulnerable people in society who require policy that protects them, absence of such policy could result in vulnerability for organisations and ultimately governments. Hence, as Beacock (2000) asserted in a conference presentation entitled 'Organisational Culture', the whole notion of vulnerability is likely to be at the forefront of policy development throughout the next decade.

The use of power is a way in which people can control others and the environment about them. Within care services over the years staff have used power to subjugate clients and to have them fall into line with the routines of life within institutions. Even the dominant theory of normalization espoused by Wolfensberger has over the years been misinterpreted by people and misapplied in order to satisfy the need for order. Indeed Brown and Smith<sup>2</sup> (1992 *pp* 172 – 173) opine that Wolfensberger's supporters stressed the need for control over a set of ideas, the challenging nature of which made them open to attack and distortion whilst his detractors have seen this control as yet another form of the very oppression normalization seeks to overcome.

Richardson (1997) writes of the utilization of nursing models in the development of care planning with the early use of problem solving models

and he suggests that learning disability nurses eventually contested those models as they realised that such an approach placed the problem within the person and they recognised this as a form of oppression. He further suggests that nurses can have an important role in the care of people who have learning disabilities and who also have health care needs but he advises that the focus of assessment should be with an emphasis on a social barriers model. Richardson believes that if barriers are omitted outcomes for disabled people are likely to be less than satisfactory. Thus, unless careful thought is given in adopting a particular approach, people are oppressed by those who are employed to support them.

## 2.7 Power and empowerment

Power and empowerment are two increasingly familiar concepts used in a variety of contexts ..... girl power, people power, military power, consumer empowerment and patient empowerment are terms frequently encountered in literature. Empowerment has become a catchall phrase, to the extent of meaning anything that denotes human activity (Nyatanga and Dann 2002).

Power and empowerment are inextricably linked. Nunkoosing (2000) referring to Rappaport and Stewart writes 'every generation will be faced with certain abstract questions of morality, fairness and justice and so on that will only find answers in social arrangements'. He goes on to suggest that often the development of understanding of learning disability has been to serve the particular purposes of different vested interests and has failed to capture the knowledge that men and women who have learning disabilities have about their experiences. Furthermore he posits that central questions of our time about empowerment, participation and emancipation are unlikely to be meaningfully addressed if we continue to give supremacy to the knowledge claims of professionals and academics. People First<sup>1</sup> (*accessed 11<sup>th</sup> August 2003*) claim 'we know what it is like not to have much power in our lives' and 'to have other people making decisions for us'.

### 2.7.1 *Power*

Here power is considered in relation to the relationships between care staff and people who use services and in particular people who have learning disabilities. In the context of this study, power relates to authority and right.



In their analysis of the essence of power, Kuokkanen and Leino-Kilpi (2000 pp 237) suggest that power is extra-personal in that increase of power for one person must be compensated by someone else surrendering part of their power. Sneed (2001) states;

power is the ability of a person or group of persons to impose their will or desires on another person or groups of persons in order to influence and alter their behaviour

Suggesting that power can be used or misused Sneed states power is in the eye of the beholder and is neither good nor bad but she suggests that how an individual uses power ultimately colours the perception of power in the view of others describes three different types of social power:

- *Legitimate power* (position or official power) is the power that comes from internalised values in one person which dictate that another has a legitimate right to influence and that he or she has an obligation to accept that influence. She cautions however that the notion of legitimacy requires a code or standard, accepted by the individual, which gives the external agent the right to assert power. Leaders achieve this type of power from such things as age, intelligence, *etc.*
- *Referent power* or personal power. A leader with this type of power to develop followers will have done so through strength of personality, charisma and magnetism.
- *Expert power* results when someone attributes to another individual knowledge or skill that he feels is necessary to meet his own goals. This type of power may only be attributed in a small number of content areas.

Richardson (1997) sees personal power as synonymous with independence and 'control over one's life rather than doing things for yourself, unassisted'. Drawing on literature, and specifically to the writings of disabled authors, he suggests that to insist on 'independence' in the form of 'do it yourself' is a form of oppression because it individualizes disability rather than viewing it in social terms, thus depoliticising disability and conveniently placing the onus once again upon disabled people to cope and adapt to an able-bodied world.

In an article entitled 'In case of loss of power...' Northway 2001 writes of an occasion when guidance dropped through her letterbox on what to do in the event of electricity supply failure. But, she said, people who have learning disabilities and who experience loss of power [*i.e.* autonomy] have no clear means of seeking assistance and she questions why this should be so. She

suggests that professionals need to critically reflect on their own practice, the services in which they work and the society in which they live and where modifications are required. Northway asserts that professionals need to work in partnership with people with learning disabilities to ensure they use their power to bring about change rather than exercise power over the people with whom they work. Nyatanga and Dann (2002) refer to the paradox of the paternalistic professional - patient relationship where the professional governs care delivery practices while espousing the empowerment philosophy.

The Nursing and Midwifery Council [NMC] (NMC accessed 14<sup>th</sup> February 2003<sup>1</sup>) recognise that the control that some nurses exert over clients is one of the ways in which abuse is able to happen.

Jackson (1999) states that professional power resides in:

- access to relevant knowledge, experience and expertise which it is claimed is only available to members of the profession
- the authority to take decisions which affect the lives of others
- being able, on terms favourable to the profession, to dispense or withhold information from service-users
- being able to structure face-to-face interaction, *such as* meetings, in ways which are advantageous to the professional
- successfully perpetuate the mystique and notion of exclusivity surrounding professional knowledge and expertise.

### 2.7.2 *Professional Power*

Research into issues of power and control in mental health community nursing (Muir-Cochrane 2000) indicated that both nurses and patients viewed nurses' as powerful. Muir-Cochrane makes reference to the need to declare openly their roles as agents of social control. This has some resonance for the current thesis in relation to learning disability care services where little reference is made to power or control with the preferred approach being to use psychological terminology to describe strategies used in care management. Nally and Steele (1992 *pp* 58) emphasise how damaging some behavioural methods can be if applied badly giving as an example: punishment for disobeying 'rules' rather than on rewards for 'good behaviour'. And they suggest that psychologists have, in recent times, moved away from correctional approaches towards more positive approaches but, according to

Nally and Steele, the litmus test of how behavioural methods are used is the way the worker's value system influences the aims and the process of work.

In a discussion on the ethics of behaviour modification, Reinders<sup>2</sup> (2002) makes use of case study to analyse the issue. He suggests that case studies illuminate moral problems to the extent that the world of moral experience they express is commonly shared. Moreover he suggests that a hermeneutical approach to this enables us to understand moral conflicts between different worlds of experience. *For example* the psychologist suggests a course of action that might result in displays of violent behaviour towards care and nursing staff whilst those staff might abandon the programme because, from their perspective, it is advantageous to avoid the potential violence. Throughout Reinders questions whether the end justifies the means and he poses:

An important aspect of effective implementation of programmes for behaviour modification may be the management of maladaptive staff behaviour.

Crosskill and Bano (1992 *pp 161*) highlight research done by Mulhern relating to sexuality of men and women who have learning disabilities as indicative of the power staff have over clients in that, even as they acknowledge that challenging behaviour can be the result of sexual frustration staff deny people opportunities for such expression in a way they would not tolerate in their own lives. They further suggest:

'Institutionalisation tends to produce people who are amenable to control and dependent on direction and it is in the power differential that some professionals find their job satisfaction'.

Beacock (2003) writes of the scandal of abuse where such scandals are generally associated with the actions of cruel or scheming people who exploit individuals or groups and where abuse has been systematic and widespread society is right to express indignation. Society should be equally outraged where abuse is less widespread as both widespread abuse and single acts of abuse within care settings are abuses of power by care staff.

In a case report of a sexual abuse Green (2001) recounts that a learning disabled woman was subjected to testing to ascertain her level of learning disability, her sexual knowledge and her ability to consent to sexual activity in

an informed way before it could progress through the justice system. Though this article related to English law it is typical of the way in which people who have learning disabilities would be assessed in Scotland in similar circumstances. Green's report highlights the tremendous power of care staff when she writes:

'Ms S had said that she had been afraid of her carer, who was physically much bigger and whom she said could 'make her life hell' if she resisted. Under the circumstances, it was argued that the carer's power undermined Ms S's ability to consent'.

In relation to nursing, consent is considered by Aveyard (2000) as autonomous authorisation and she asserts that clearly the doctrine of informed consent can be applied only to those patients who have sufficient autonomy to make their own decisions. Aveyard suggests that we need to draw a distinction between those who are able to consent and those who should be cared for in their best interest. It is in the latter situation where care staff within learning disability services may argue for a protectionist approach to care in order to avoid the possible consequences of taking calculated risks.

According to Aveyard however though the term autonomy is used in nursing it means different things to different nurses and she suggests the haphazard use of the concept serves to highlight the confusion and ambiguity present but does not assist clarification. According to Meininger (2001):

The dominating concept of autonomy is largely orientated toward realization of the self into a sovereign individual and toward an emancipation that is aimed at freedom of choice and self-determination.

The ambiguity articulated by Aveyard, it could be argued, is similar to the ambiguity with the word empowerment which is discussed more fully at 2.4.2. However though both empowerment and autonomy are concerned with emancipation there is a clear distinction; the former requires that another gives up power whilst the latter, according to Meininger (2001), is concerned with the continuous disassociation of the self again and again from all those bonds which present themselves wholly or partially as relations of unequal power. Meininger opines that the emancipatory character of this conception is a clear expression of the necessity of a right to autonomy in order to protect the weak from the unbridled and authoritarian self-realization of the strong and he

suggests that as in the professional care setting the care giver is the stronger party, the right to autonomy and the respecting of that right must promote the view that this relation is guided by the priorities of the care-receiver rather than those of the care giver.

In a Scottish study, within learning disability health services, Young (2002) reported on her research into the use of Goal Attainment Scaling as an individualised measure of outcome within two acute specialist in-patient units. She commented that 'A consistent preference for individualised measures for outcome for people with learning disabilities emerged'. However she went on to note that 'the research indicated multiple perspectives on stakeholders' attitudes to partnership working, regarding *for example* power differentials, professional territorialism and interagency mistrust'. Referring to power dynamics, Griffin (2001) concludes that those 'that are able to work within power dynamics of the healthcare environment comfortably and effectively will be those who are:

- comfortable with the concept of power and developing or exerting influence;
- able to appreciate and function effectively in the political climate in which they are working;
- assertive
- have good negotiation skills; and
- have the necessary skills to actively influence decision making within the healthcare team.

Thus in this instance power is certainly viewed in a positive light, whilst other views of professional power are viewed less favourably.

Sines (1995) refers to a total institutional model. Dominance is a key theme, with managers dominating frontline staff who in turn dominate the clients, which he further describes as a form of social control. He cites Tichen and Binnie when he suggests that to challenge the traditional method of practice within institutions there needs to be a re-examination of values and re-negotiation of existing skills and new role and power relationships. Nunkoosing (2000) takes the reader to a point where it becomes necessary to reflect on how knowledge, which is power, affects social actions. He implies powerlessness and even vulnerability on the part of those who support people whose behaviour is described as 'challenging' and he asserts that the term

*challenging* ‘has become a way of describing all the things we do not know how to deal with in the lives of men and women with learning disabilities’. However, he suggests that as services embrace the consideration that people’s behaviours challenge services to provide environments which support alternative behaviours has to reject older explanations of learning disabilities. Nunkoosing cautions however that ‘both persons with learning difficulties and we ourselves are trapped by the prevailing discourse of power’.

Risk assessment is an important feature in planning care. In no situation is this truer than one where care staff feel they have lost control when a person displays violent or aggressive behaviour. Use of control and restraint can be seen as a punitive measure and if used it must be closely evaluated for its effectiveness. Kaye and Allen (2002) suggest that control and restraint training for care staff should be based on a reflection of the pattern of aggression seen on a day-to-day basis rather than on reported incidents that are likely to be more severe. However such an approach could leave both service users and staff vulnerable if people are not skilled in dealing with more problematic behaviours albeit less frequent ones, and risk assessment must be based on an eclectic approach to data gathering in relation to those risks.

The product of risk assessment is dependent on the reason underpinning such an assessment. *For example* Stein (2005) recommends the use of the Needs Assessment Schedule (NAS) (Sainsbury Centre for Mental Health *accessed 19<sup>th</sup> March 2007*<sup>1</sup>) and he suggests it has the potential for forming a basis in joint-working with partner local authorities for the allocation of care resources. This is clearly important for service planning purposes however the focus is understandably on the potential risk impact to the organisation which is based on:

- ‘Past behaviour’ ... covers any time in the patient’s past outside of the rating period, ever.
- ‘Physical aggression’ ... is defined as a continuum of behaviours that includes mild aggression (e.g. blocking one’s path, minimal physical contact such as a mild push or poke with a finger) to severe physical aggression (e.g. a serious physical assault).
- ‘Vulnerability to others’ ... concerns previous evidence, or current risk, of vulnerability in terms of crime, violence, threats, bullying or exploitation posed by others.

The collective data are then used to re-code clients into one of three ‘risk’

groups: a) the 'no risk' group, b) the 'moderate risk' group and c) the 'severe risk' group.

An alternative approach to risk assessment places the individual at the centre of care planning of which risk assessment is an integral part. In an exploration of whether or not person-centredness matters McCormack (2003) draws attention to some enabling features of which he lists a number of enabling factors. In relation to person-centredness and its relationship to enabling risk management he highlights the need for:

- An understanding of professional boundaries in decision-making.
- An understanding of responsibility and accountability in professional decision-making
- A person-centred approach to risk assessment and risk-taking.
- A willingness to make explicit intent and motivation for actions.

Price (2006) however cautions that 'Difficult' or non-compliant patients represent a severe test of the extent to which care can be person-centred. He points out that negotiation with the difficult or non-compliant person is a necessary skill. Price suggests that failure so to do might result in failure to help the person make his own choices about lifestyle change. This in turn leads to feelings of lack of control. Lack of control and lack of influence are independent risk factors for stress (Sainsbury Centre for Mental Health accessed 19<sup>th</sup> March 2007<sup>2</sup>).

According to Holman (2001), we know many people with learning disabilities suffer abuse at the hands of those who are placed in positions of 'care' and the perpetrators of abuse are not often likely to be found out and are therefore able to continue their trail of abuse. Reporting on a conversation with Nicola Harney, a London based solicitor who specialises in personal injury and criminal injury claims of people who have learning disabilities, he quoted her as follows:

'This [abuse] can include physical, sexual, emotional or psychological abuse but also includes restraint, neglect, the provision of inappropriate services and treatment or the withholding of appropriate services or treatment ....[and can occur] whenever there is a power imbalance in a relationship'

Recent government policy (Scottish Executive 2000) has emphasised the need

for a shift in power in that they recommend the development of person centred planning. Implicit in the development of such plans is the need for the individual to be at the centre of planning and that power is shifted towards him or her. This has created tensions for staff who have believed that they have always acted in the best interests of their clients.

### 2.7.3 *Empowerment*

Empowerment has its origin in the Latin verb for power, *potere* which means 'to be able'. Its prefix 'em' means 'cause to be or provide with'. Empowerment therefore represents both a process and an outcome ..... (Nyatanga and Dann 2002). Zimmerman and Warschausky (1998), in their discussion on empowerment, suggest there has been a paradigmatic shift from a focus on deficits and dependence toward an emphasis on assets and independence as is evidenced in the terminology shift from patient to consumer and more recently to constituent and they opine that empowerment theory provides a useful framework for guiding our work as the field becomes more constituent based. Empowerment implies involvement, control and ability to make choices (Mir and Nocon 2002). The acquisition of power leads to independence and disadvantaged people can benefit from the services of an advocate to support them in making that transition. Citing the work of Atkinson, Mir and Nocon (2002) state that advocacy services aim to increase autonomy, self-determination inclusion and provide a voice in the way services are offered. Zimmerman and Warschausky (1998) speak of empowerment values as a belief system that governs how professionals and clients work together. Whilst this is true it should be recognised that the terminology used to describe the parties within this value system; clients and professionals, infers if it does not make explicit the inequality of power within service relationships. The former is: a user [of professional services] whilst the latter conveys a level of skill based on specialised training. It could therefore be argued that however hard professionals try to support or create the conditions for empowerment, the inequality within the relationship is evidenced in the perceived giving nature of the professional and the receiving nature of the client. Jingree *et al* (2006) write of the dilemmas of staff when they state:

There is a tension between staff encouraging residents to make their own choices and shepherding them towards choices which the



staff, for various reasons, might prefer. Some of these reasons may well be institutionally appropriate, but the effect nevertheless is directive, and contrary to the aim of encouraging free expression.

Gilbert (1995) asserts 'how do we [nurses] work to empower others when we have no clear notion of what power is?' He further argues that the effects of power must be identified in that the forms of social practice it produces should be made explicit. Gilbert asserts 'the consequence of leaving power under-conceptualized is a tendency to consider that empowerment can be achieved solely through enabling strategies such as providing information.

According to Jackson (1999) 'it is generally recognised that one of the principal aims of advocacy is the empowerment of disadvantaged individuals and groups'. However, he points out that it is not widely appreciated that advocacy is as much about disempowerment as it is about empowerment and that, in effect, this situation requires that power is wrested from the 'losers' who he identifies as being the professionals. It was stated in a facilitated workshop (Anon. 2003<sup>2</sup>) we (society) have given a name to describe how a person speaks for him/herself: self-advocacy. This participant continued by suggesting that those who do not have learning disabilities do not consider that speaking up on their own behalf is advocacy.

Kuokkanen and Leino-Kilpi (2000) refer to empowerment as an abstract concept that is fundamentally positive, referring to solutions rather than problems. They further suggest that, as empowerment is associated with growth and development, accordingly the process requires introspection and changing patterns of activity. Chinn (2000) states that she has heard colleagues objecting to the word empowerment as a fad, a trend, a trite term that carries little meaning and she conjectures that this is partly because it carries so many diverse meanings. She cites lack of alternative vocabulary to describe the process by which people become able to act from a source of inner strength, able to sustain against all odds and are capable of taking matters into their own hands, as reasons for the expressed views of colleagues. Chinn suggests that 'to quibble over nuances of meaning in a term with no good alternative meaning when the interests of those whose vulnerabilities we seek to ameliorate are at stake, we sacrifice important opportunities by dismissing a dynamic that could make a world of difference'.

Zimmerman and Waurschusky (1998) refer to empowerment processes and empowerment outcomes. They present empowerment process as the development and practice of skills necessary to exert control over the socio-political environment and learning to critically analyse it. As an example of empowering process they refer to research in which individuals were involved in goal setting for treatment outcomes and treatment gains were maintained 2 months after the intervention, whilst less involved adults did not maintain gains in the same way. Empowerment outcomes are defined as consequences of empowering processes *such as* control awareness and participation. Thus, it can be argued that empowering organisations should strongly support empowering processes if they wish to improve success in supporting people to achieve desired outcomes.

Jenkins (1997) also describes empowerment as a rather more complex phenomenon and asserts that the word 'empowerment' is ambivalent and implies vulnerability on the part of the client and it is further suggested that those who need to be empowered often cannot be.

This view is shared by Nyatanga and Dann (2002) who argue that nursing cannot empower patients unless they address the hierarchical mindset and internalise the empowerment philosophy in which individual experiences and choices are truly respected. They write 'as long as service users are referred to as patients and are expected to comply with the sick role then empowerment will remain an ideal that will never be realized'. Nyatanga and Dann (2002) state that the ideals and visionary frameworks of empowerment will not empower individuals unless there is internalisation of the philosophy and practice of empowerment.

Faulkener (2001) cites Gibson's (*Gibson 1991*) definition of empowerment as:

'A social process of recognizing, promoting and enhancing peoples' abilities to meet their own needs, solve their own problems and mobilize the necessary resources in order to feel in control of their lives'.

Faulkener goes on to suggest that 'it is therefore implied that patient independence may be optimized through the provision of empowering care which assists patients to gain control over their lives'.

Sines (1995) states that:

‘Features related to institutional methods of care delivery continue to exist in some of our long-stay hospitals today and clients may still be expected to conform to the dominant themes of time, order, control and regimentation’.

He suggests that ‘the challenge of empowerment and enhanced autonomy is considered to be at the cutting edge of the learning disability agenda’. With regard to quality in services, Sines claims that any human service that aims to provide high-quality provision must be needs-led within its management culture (Sines 1992 *pp.* 63).

There are many different interpretations of empowerment in nursing which have been well detailed by Gale (1998). However the main focus of her paper is professional empowerment of learning disability nurses and she points to the need for those nurses to articulate their views of learning disability nursing in a revolutionary way to bring about change. Rich (1998) supports this view and suggests that empowerment requires staff to feel committed to philosophies of care, as well as the policies and procedures of service provision. Empowerment has been the subject of much debate in recent years as a philosophical shift has taken place which sees client empowerment as a fundamental right. Nevertheless it is suggested that people cannot be empowered by others and can only empower themselves (Oliver *as cited by* Jenkins 1997).

In his paper entitled Policy to Practice, Malin (1997) highlights the potential conflicts that emerge in contemporary services where 2 different models – consumerism and empowerment – are used to maximise client satisfaction. The former, with its focus on desirable and profitable sources, is derived from commercial and consumerist interests whilst the latter is derived from the self-advocacy movement’s agenda of empowerment in the sense of people achieving more control of their lives.

For empowerment to be effective both carer and the cared for person need to change behaviours with the former giving up power whilst the latter assumes power. It could also be argued that it is powerful to have the power and to give that power away. Some care staff fear they will lose control of challenging situations if clients become more powerful and this was reflected

in research relating to person-centred planning (Parley 1999). However, for people who have been disenfranchised for so long claiming back power is a tall order. Like many other authors, Jackson (1999) believes that citizen advocacy has the potential to transform the lives of people who have learning disabilities but he cautions that an inevitable consequence of client empowerment is professional disempowerment.

The report of the 21st Century Social Work Review entitled 'Changing Lives' proposes personalisation of services to match the country's expectations for high quality, accessible, responsive and personalised services based on core values of inclusiveness and requiring cultural change in the way in which statutory, voluntary sector and the private sector respond to changing needs of those using the services (Scottish Executive 2006).

## 2.8 Vulnerable adult

The term vulnerable adult was the subject of a consultation exercise by the Scottish Executive and the findings were reported in a paper entitled Consultation on Vulnerable Adults: analysis of the responses (Scottish Executive 2002). The Scottish Law Commission's definition of a vulnerable adult which was the basis of the consultation was:

'An adult aged (16 or over) who is unable to safeguard his or her personal welfare, property, or financial affairs,

*and is:*

in need of care and attention arising out of age or infirmity, or suffering from illness or mental disorder, or substantially handicapped by any disability'.

Only 14 out of 59 respondents agreed with the aforementioned definition: some respondents agreed with the definition but felt that it should include the concept of risk as it was argued a person might fit the definition but not require intervention. The report concluded that the definition 'came under scrutiny, particularly with regard to terminology and stigma'. It was also felt that autonomy of the individual could be over-ridden if certain circumstances prevailed. Although there would have been some benefit in considering a global perspective regarding the concept of 'vulnerable adult' the absence of a definition of 'vulnerable' in the legislation rendered this impossible.

The Nursing and Midwifery Council [NMC] (*accessed 14<sup>th</sup> February 2003<sup>2</sup>*)

also suggested there may be circumstances in which the practitioner should consider breaching confidentiality in the client's interest. This, to an extent, flies in the face of recent legislation where the principles of the Adults with Incapacity (Scotland) Act 2000 are that all decisions made on behalf of the adult with impaired capacity must:

- benefit the adult
- take account of the adult's wishes and the wishes of the nearest relative or primary carer, and any guardian or attorney
- restrict the adults freedom as little as possible while still achieving the desired benefit
- encourage the adult to use existing skills to develop new skills.

Tensions may arise with regard to protection where the primary carer feels the risk is too great whilst the adult who may be considered lacking in capacity to make informed decisions wishes to take that risk. One life experience that raises such emotions is that of sexual relationships for people who have learning disabilities. Often families and care staff fear the consequences of close and intimate relationships and so deny them. Services are seldom designed to support intimacy even where close relationships exist so collusion between service staff and family members can result in decisions that are inconsistent with the wishes of the disabled person.

In its guidance document entitled 'No Secrets' the UK parliament called for 'agencies to work together to ensure a coherent policy for the protection of vulnerable adults at risk of abuse with the primary aim being the prevention of abuse where possible but if that strategy fails ensuring a robust policy is in place for dealing with abuse incidents'. In the document the definition of a vulnerable adult offered is 'a person who is or may be in need of community care services by reason of mental or other disability, age or illness and who is or may be unable to take care of him or herself, or unable to protect him or herself against significant harm or exploitation'.

People with learning disabilities can be vulnerable because of inability to defend themselves from abuse. They can be even more vulnerable as the perpetrator of abuse may have knowledge of the communication difficulties of the victim and consider this to be a safety barrier. This was the view of Ericson *et al* in the early 1990s (1994) and they elaborate that this perceived

communication difficulty that is sometimes interpreted as lack of witness competency within justice systems and should be addressed with the burden shifting to the health and legal professionals to become competent interviewers. Bailey (1997) echoes this view and elaborates when the author cites Mundy and Thomas who suggest that, in addition to communication difficulties, the vulnerability of this client group may be due to the dependence of learning disabled people on their carers. This may 'encourage a culture of unquestioning compliance and trust together with a strong desire for acceptance and need for approval from others'.

Since 2004 however the law is such that 'the court must not, at any time before the witness gives evidence, take any step intended to establish whether the witness understands those matters'.

Across the country appropriate adult schemes have been set up to support vulnerable people through the process of interviews of this nature. According to Lynne Walsh who is an Appropriate Adult (Walsh 2000):

'Police officers and other professionals are really diligent, but custody suites are busy places and they can't always notice if a detainee is not quite understanding. We are there to ensure communication is as good as it can be and that interviews are conducted properly and fairly'.

The suggestion of Ericson *et al* (1994) to improve interviewer competence might through time reduce the need for third party presence.

## 2.9 Protected adults

More recently the term *protected adult* has gained prominence. Williams (2002) called for legislation that has in its essence the European Convention of Human Rights, which imposes a duty on states to protect vulnerable adults, but that such a law must pay cognizance to the right under the convention to a private life. He asserts that any new law 'must carefully balance these two (often competing) rights'. But it was not until the murders of Holly Wells and Jessica Chapman, two children, in Soham in 2003 and the subsequent inquiry that Safeguarding Vulnerable Groups Act 2006 was enacted.

As a result of the Bichard Inquiry, several recommendations were made that led to additional protective measures being implemented *such as* improved information management and increased vetting and enhanced disclosure of

people working with children and vulnerable adults. Although the Bichard Report made recommendations for England and Wales the Scottish Executive were keen to bring forward proposals in Scotland to ensure that there were no cross-border loopholes that could be exploited (Harvie-Clark S and Berry K 2006). The Bichard inquiry materialised in the Safeguarding Vulnerable Groups Act 2006. For the purposes of this Act, a *vulnerable adult* is an individual aged 18 or over and who lives in residential accommodation, receives domiciliary/healthcare/welfare services and requires assistance in the conduct of his own affairs.

In the Adult Support and Protection (Scotland) Act 2007 *Adults at risk* is the chosen term. *Adults at risk* are adults who:

- (a) are unable to safeguard their own well-being, property, rights or other interests,
- (b) are at risk of harm, and
- (c) because they are affected by disability, mental disorder, illness or physical or mental infirmity, are more vulnerable to being harmed than adults who are not so affected.

Though the focus of this legislation sees a shift from a focus on vulnerability to one on support and protection it nevertheless includes vulnerability in the definition of an *adult at risk*.

## 2.10 Abuse

‘An unknown number of people with learning disabilities have experienced unthinkable horrors - including exposure to the scarring experiences of frequent and erratic ‘punishment’, gross neglect, systematic sexual abuse, long-term bullying and victimisation, and just as painful - the denial of such experiences within the context of minimisation’

(National Development Team *accessed 22/11/00*).

The word abuse is both a noun and a verb but in this study the focus is on the noun. It originates from the Latin *abuti* ‘misuse’ and is defined as **1** the improper use of something. **2** cruel and violent treatment, especially sexual assault. **3** insulting and offensive language (The Compact Oxford English Dictionary of Current English *accessed 18<sup>th</sup> October 2006*).

Cambridge (Cambridge Dictionaries Online *accessed 18<sup>th</sup> October 2006*) states abuse is when someone uses or treats someone or something wrongly or

badly, especially in a way that is to their own advantage: an abuse (= wrong use) of privilege/power/someone's kindness sexual/physical/mental abuse (= bad treatment).

Abuse can take place in many different settings and may happen privately or in public places. In parliament, Scott Barrie, MSP, spoke of the bullying and harassment of people with learning disabilities (Barrie 2000). He stated:

‘people often regarded victimisation in communities as less severe than their previous experiences of abuse in long stay hospitals and therefore felt that such victimisation should be tolerated’.

Walker (1993 *pp* 209) states ‘as the private residential sector mushroomed, evidence mounted of abuse, misuse of drugs, fraud, lack of hygiene and fire hazards in some homes’. He adds that evidence of abuse in the private sector inevitably invites comparison with the public sector where similar instances of abuse are to be found and draws attention to the fact that this sort of comparison diverts attention from the key issues:

- Operation of power in residential settings
- Which of the two sectors can be regulated to ensure that no abuse of power occurs.

Nevertheless it should be noted that regulation can go some way toward creating a safer environment within care services but it could never guarantee to eliminate abuse. Assessment of risk too can serve a useful purpose in deciding along with relevant people and with the learning disabled person at the centre of that discussion how best to support him/her to achieve what they want from life.

Broadly speaking the care sector is divided into two main categories; the statutory or public sector and the independent sector. The National Health Service (NHS) and the Local Authority are the organisations that make up the public sector. Churchill (1992 *pp* 23 – 24) suggests that the term independent sector is ‘like many umbrella terms, a little confusing’. However he elaborates that the independent sector comprises all those organisations providing services other than the statutory services, *such as* the private sector and the voluntary sector including housing associations, charities and not-for-profit organisations though he counters that some are so closely governed as to fall into no-man’s land. Regulation within services is a key feature of review,



which can go some way to ensuring that processes are in place to address concerns regarding, amongst other things, protection of those served. Under the Regulation of Care (Scotland) Act 2001 the Scottish Commission for the Regulation of Care was set up for the purpose of furthering improvement in the quality of care services provided in Scotland. In addition, it sought to make provision for the registration and regulation of care services, and for the registration, regulation and training of social service workers, amongst other duties.

Legal redress has often been denied people with learning disabilities however recent years have seen some progress in this regard with the introduction of the Vulnerable Witnesses (Scotland) Act 2004, appropriate adult schemes and guidance for improved police interview techniques and legislation. However research, commissioned by the Scottish Executive on the recommendation of the Millan Committee, showed that the appropriate adult schemes were underused and not everyone who needed such help was being offered it (Thomson *et al* 2004). It is also questionable how helpful the Vulnerable Witnesses Act will be in protecting people. Whilst it provides support to individuals through what could be a traumatic process offering a degree of protection from the defendant in the court setting it does not actually protect people from the abuse. However it must be acknowledged that the introduction of this legislation must have been based on the assumption that there will always be vulnerable people and potential abuse hence a need to support people through the legal system after the event.

Much of western world policy is developing against a backdrop of lawsuits, *for instance* Ranseen (1998) refers to the many litigations under the Americans with Disabilities Act and the need for specific testing accommodations for people with learning disabilities. Sadock and Sadock (2005) commented:

Sparked by a series of lawsuits in the 1970s controversies still rage about test bias and the appropriateness of IQ testing in children from minority groups; court rulings have come out against and in favor of IQ tests.

Whilst North America has led the way with this litigious approach to policy development, the United Kingdom is increasingly finding that policy must be developed in this way. Indeed in the United Kingdom the NMC (NMC 2002<sup>2</sup>

pp 12-13) acknowledges the high cost of litigation and recommends development and implementation of robust policies and procedures for the management of abuse as a means of avoiding such costs.

It is only in the last decade that governments have started to take cognisance to the pleas of campaigners calling for zero tolerance of abuse. Abuse is not only directed at people with learning disabilities but also others who might be described as vulnerable people, *for example* children, elders, people in violent domestic situations, etc. However, it is argued that people who are abused should not necessarily be considered vulnerable unless they are unable to report the abuse for him/herself (Hansen and Stout 1997).

In their publication entitled *Living in Fear* Mencap (1999 pp 17) reports findings of their research in which it is stated that 75% of people with a learning disability who had been bullied reported the incident to a person in authority. *For example* they reported that people with learning disabilities informed staff members, family members or occasionally police however in 53% of those cases the bullying did not stop. It was felt that this was due to the victim not being listened to and taken seriously and this is reflected in the advice given by those authority figures *i.e.* ignore the behaviour or walk away. Sharp (2001) reflects on this and suggests that it is not lack of desire to provide satisfactory policing that results in people with learning disabilities being denied equal access to the justice system. Rather it is lack of training of police officers with a summary of a Home Office Police Research Group highlighting that 80% of police officers had not received specific training relating to people with learning disabilities and that communication problems and attitudes were the problems encountered in dealing with those individuals.

In a discussion of the feminist perspective of normalisation Brown and Smith (1992 pp 167) write of the similarities between the oppression of people with learning disabilities and oppression of women. In relation to abuse they suggest it is wrong to invite people to hide their experiences of victimisation in the belief that such disavowal will protect the ideals of community care. Instead they assert that carers and professionals, who are often women, should ally themselves with individuals who have been abused, insulted or deprived of rights and help them to make this knowledge public.

In recent times Mencap has reported high profile abuse cases in independent care homes (2005) and in a Partnership NHS Trust (2006). In both there were subsequent external reviews. These are examples of a many such cases as can be seen frequently in local and national newspapers.

In an English study of social care and health services for people with learning disabilities (DOH 1999) it was reported that although there was evidence of interagency policy development relating to detection and investigation of abuse, one fifth had not agreed such policies and only half had implemented staff training. It was further reported that there were difficulties concerning work across agencies, including the criminal justice system.

In the aforementioned document 'No secrets' it was proposed that the development and implementation of multi-agency policies and procedures for protecting vulnerable adults should be progressed.

#### *2.10.1 Global perspective on abuse*

Domestic abuse might reasonably be considered as a 'catch all' term since every citizen has a living situation, which for him/her is domestic, therefore within that setting anyone might be exposed to abuse. Within that 'catch all' though there will be various subsets: women, children, elders, people with disabilities, etc and there is increasing research in each of those categories with child abuse receiving the greatest attention followed by elder abuse. Research relating to people with disabilities though increasing is still limited and largely focuses on sexual and physical abuse.

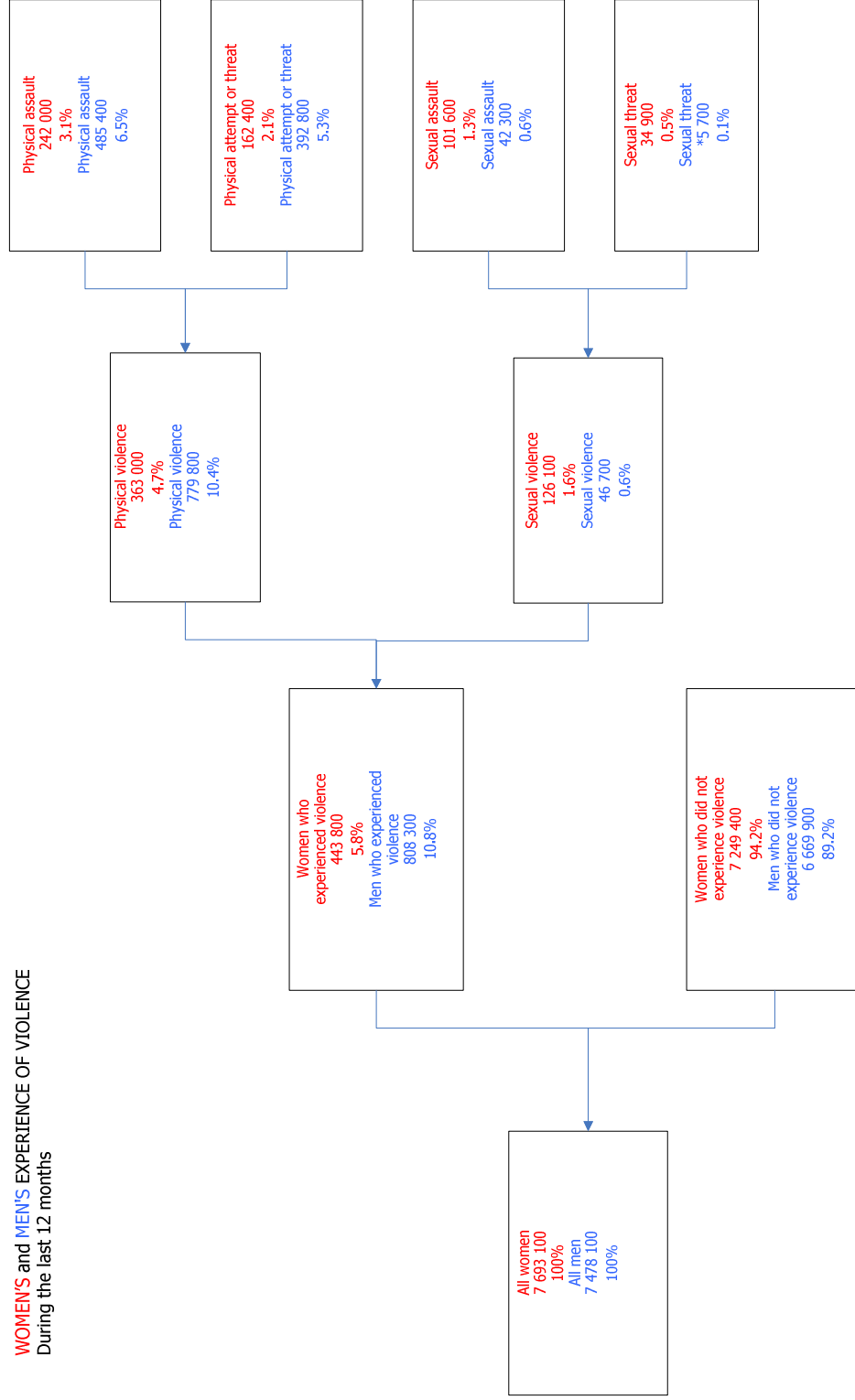
People find the notion of abuse objectionable. Nevertheless reported instances of abuse within society are high with abuse reported daily in the press. *For example* frequent reference is made in the media that high numbers of women are subjected to domestic abuse. To illustrate this point it was reported that the Scottish Domestic Abuse Helpline received 20,410 calls in 2005, an increase of 5,634 on the previous year (Scotsman 17<sup>th</sup> June 2006). The Guardian reported that one in four adult women has experienced at least one physical assault from a partner during adulthood, and one incident of domestic violence is reported to the police every minute (Guardian 9<sup>th</sup> August 2006).

The Australian Government conducted a study of domestic violence specifically as it relates to physical and sexual abuse. Under the banner of

domestic abuse the survey was conducted between August and December 2005. The definition here included physical and sexual abuse but made no specific reference to any other type of abuse. Although the threat of sexual or physical abuse was included, it was not named as either emotional or psychological and was only included if the recipient of the threats believed that the person making the threat would in fact carry it out. The data indicate more men than women (ratio 2.15:1) claim to have been subject to physical violence in the domestic setting whilst more women than men (Ratio 2.7:1) claim to have experienced sexual violence. Though reports of domestic abuse more often relate to women this data would indicate that there are indeed many men subject to domestic abuse. Thus true abuse statistics may be masked by societal assumptions that those considered to be weaker such as women, disabled people, elderly people are more likely to be subject to abuse.

The data of the Australian study are represented in Figure 2 overleaf.

**WOMENS and MENS EXPERIENCE OF VIOLENCE**  
During the last 12 months



Women and men who experienced violence during the last 12 months could have experienced violence more than once. The components when added may therefore be larger than the total.

\* estimate has a relative standard error of 25% to 50% and should be used with caution.

Figure 2. Adapted from 2 diagrams in the personal safety survey, Australia (Australian Bureau of Statistics (2005 pp 5 and 6))

In America domestic abuse has a much more detailed definition:

Physical abuse: Verbal threats of violence, pushing, shoving, hitting, slapping, punching, biting, kicking, holding down, pinning against the wall, choking, throwing objects, breaking objects, punching walls, driving recklessly to scare, blocking exits, using weapons

Emotional/Verbal abuse: Name calling, coercion and threats, criticizing, yelling, humiliating, isolating, economic abuse (controlling finances, preventing victim from working), threatening to hurt children or pets, stalking

Sexual abuse: Unwanted touching, sexual name calling, false accusations of sexual infidelity, forced sex, unwanted pregnancy, sexually transmitted diseases, HIV transmission.

National Center for Post Traumatic Stress Disorder, United States Government (*accessed 20th August 2006*)

On this website the prevalence of abuse in America is estimated and is replicated in the table below though the only direct correlation between the American data and that of the Australian data relates to physical abuse where more men than claim to have been abused in this way in Australia whilst American data show the reverse (Table1).

- |   |
|---|
| <ul style="list-style-type: none"><li>* 20-30% of American women will be physically abused by a partner at least once in their lifetimes</li><li>* 1.3 million women and 834,732 men are physically assaulted by an intimate partner annually</li><li>* 201,394 women are forcibly raped by an intimate partner annually</li><li>* 11% of women in homosexual relationships and 23% of men in homosexual relationships report being raped, physically assaulted, and/or stalked by an intimate partner</li><li>* 503,485 women and 185,496 men are stalked by an intimate partner annually</li><li>* 1-25% of all pregnant women are battered during pregnancy</li><li>* 30-40% of women's emergency room visits are for injuries due to domestic violence</li><li>* 30% of women killed in the U.S. are killed by their husbands or boyfriends</li><li>* 50% of men who assaulted their female partners also assaulted their children</li><li>* 3.3 million children witness domestic violence each year</li></ul> |
|---|

Table 1 American data relating to abuse.

Whilst the preceding table provides data relating to domestic abuse in America it is also necessary to consider abuse in the context of vulnerable adults policy. *For example*, in their policy the City of Minneapolis (accessed 11/10/06) not only define what they mean by vulnerable adult, they also define abuse:

**Abuse.** Generally defined as assault but also covers areas such as sexual assault, force or coercing the vulnerable adult to do acts they would not normally do, use of unreasonable acts, verbal or physical, that would be derogatory or humiliating to the vulnerable adult

**Financial Exploitation.** When a person takes advantage of the vulnerable adult's situation to obtain unauthorized money, this can include fraud, theft, forgery, and any other type of financial exploitation.

**Neglect.** The failure of a caretaker to provide a vulnerable adult with needed care or services. This includes medical, clothing, food, shelter, and supervision. The vulnerable adult may be self-neglecting as well.

Whilst the Minneapolis definitions of abuse and financial exploitation are very similar to that in Scottish legislation with the definition of abuse there is some contrast. The Minneapolis definition makes reference to the vulnerable adult whilst in the Protection from Abuse (Scotland) Act 2001 the focus is on the behaviour that is seen as abusive with no reference to the victim. In this legislation abuse is defined as violence, harassment, threatening conduct, and any other conduct giving rise, or likely to give rise, to physical or mental injury, fear, alarm or distress. Conduct includes (a) speech; and (b) presence in a specified place or area.

Research in the last decade has looked at different care groups with elder abuse, *for example* Craig (2000), Joannides (1999) and Sequiera (2005) and child abuse *such as* Devaney (2004) and Powell (2001) receiving considerable attention. Prevalence studies on elder abuse have been carried out (Pillemer and Finkelhor 1988) in the UK, (Boldy *et al* 2005) in Australia where financial abuse was identified as most common. An American study (Kennedy 2005) reported the prevalence of neglect and abuse to be sufficiently high as to make the need for accurate diagnosis a pressing one. In this article it was reported that 'paediatricians and others have worked hard to advance the knowledge base and reporting of child abuse, but a limited number of physicians are working in the area of elder mistreatment'. This comment is as valid in the UK context where child abuse receives

considerable attention followed by elder abuse, as evidenced through a search of ASLIB using the search term 'abuse'. Research relating to people with learning disability and abuse has focussed on sexual abuse, *for example* Bailey (2001) and Sequiera (2005).

In the aforementioned American study GPs and internists indicated they would be reluctant to intervene in instances suggestive of caretaker neglect and felt that making inquiries into concerns of financial exploitation to be outside the scope of their professional responsibilities (Kennedy 2005). This is of real concern if these GPs are the frontline people who first experience disquiet.

Abuse in its many forms is prevalent in society generally and it also happens within services where people are employed to care. Research into abuse within other sections of society has relevance, but there is a need for detailed study of this subject within the context of learning disability care services.

Furthermore, in an inclusive society it might be reasonable to conclude that older people with learning disabilities who have been subject to abuse would figure in the elder abuse data and likewise children. The reason for this is that specialist services for people with learning disabilities provide for those between the ages of 18 - 65. Youngsters with learning disabilities are children first and elderly people with learning disabilities requiring care and support have this provision within mainstream elderly services.

### 2.10.2 *Abuse and people with learning disabilities*

Abuse, according to the United Kingdom Parliament (2000) is 'a violation of an individual's human and civil rights by any other person or persons'.

Various campaigning bodies *for example* Enable and Mencap as well as politicians refer to bullying and harassment as abuse, whilst Values into Action (VIA) prefer instead to use the term *hate crime* to describe those types of behaviours arguing that to refer to it as bullying is to mislabel it (VIA 2002). Indeed, on this particular point the following transcript details a question put to the Scottish Executive (2003a) on 6<sup>th</sup> March 2003:

Jackie Baillie (MSP Dumbarton) (Lab): To ask the Scottish Executive what action is being taken to ensure that crime against people with learning disabilities is explicitly recognised and not



described by other terms such as bullying, harassment and abuse.

VIA argue that since physical assaults, theft and harassment of learning disabled people are being labelled bullying they are not reported to the police, and instead the victims are encouraged to stay away from risky situations and are offered counselling (VIA 2003). This is also the approach advocated by Long and Holmes (2001) based on the findings of a study involving the setting up of a 'Keeping Safe Group'. Nevertheless development of adult protection policies has been based on the terms on use of the term abuse and it is a term with which there is some familiarity amongst care staff.

Often perpetrators of abuse are people known to the victim. Bowen (1997) persuades that educational programmes about abuse should highlight this since, she argues, dearest friends will at some point have been strangers. Abuse of power is a common weapon, wielded not only over the victim but also over junior colleagues and other service users who may be tempted to report (Williams, 1995 *p.323*). Brown *et al* (1998a) *p.21* also subscribe to that view. In their Alerter's Guide they state:

'Abuse by a colleague is always going to be uncomfortable and you will need to find someone you trust before you can challenge it. You may also find yourself drawn into or implicated in practice of which you do not yourself approve. You may even have been told to do something you find unacceptable...'

Cambridge maintains that abuse of people with learning disabilities is morally indefensible and this includes the indirect toleration of abuse or collusion in relation to reporting and responding to abuse (Cambridge, 1999 *p. 285*). In a press release (Scottish Executive 1999<sup>1</sup>) relating to the launch of the report entitled 'Protecting the Vulnerable: Caring enough?' (Scottish Executive 1999<sup>2</sup>) Susan Deacon said:

'A breach of care – be it physical, verbal, emotional, sexual, financial or even an omission of care – is unacceptable and inexcusable'.

Brown *et al* (1998a *p 4*) point to the fact that abuse has a wide array of meanings and can range from spontaneous acts of frustration to systematic and premeditated targeting of a vulnerable person.

Carter (1999 *pp 28 - 30*) conducted a study into why nurses abuse and he found that 70% of nurses before professional conduct committee hearings for

allegations of abuse cases were male and 50% of all abuse cases involved nurses who had been registrants for more than 11 years. In his study he interviewed 10 nurses who had abused patients and he reveals that on reflection those respondents recognised that their behaviour had fallen below acceptable levels. *For example, one nurse accused of hitting a patient said:*

*I didn't have real insight into my conduct until a student nurse reported me. I wish I had not allowed myself to get stuck in a rut.*

Another, accused by an auxiliary of rigid and intolerant behaviour to elderly people and berating them for incontinence, said

*As I read the statement, I reluctantly began to look at myself.*

Alarming Carter was able to find evidence that some who have abused are still able to practice, *for instance* after serving a jail sentence for buggery of a small child'.

Few allegations of abuse of learning disabled people reach the courts. Reasons include reluctance on the part of the victim to attend a police station, reluctance to report and make a statement, stress related to the process and the belief that, as witnesses, learning disabled people would lack credibility therefore the case will not proceed beyond the Crown Prosecution Service. Nevertheless, cases of alleged abuse are reported to professional bodies, as reported by Carter (1999). Bradshaw (1999) reported that whilst learning disability nurses comprise only 5% of nurses on the register about 10% of those removed from the register are from this branch. He further details that 54% of learning disability registered nurses' conduct hearings over the preceding 7 years involved breaches of client-practitioner relationships:

- physical and verbal abuse (33%)
- failure to attend to basic needs (12%)
- sexual abuse (2%)
- theft from patients (2%)
- unsafe clinical practice (5%)

More contemporary figures relating to the learning disability branch of nursing are not readily available for comparison.

According to Ashton (1997) access to justice is denied them because the courts do not adapt procedures to take account of physical or communication

difficulties. Bailey and Sines (1998 *pp170*) share this view, pointing out that assumptions are often made early in a case that the victim would not be capable of giving evidence therefore a full investigation is not carried out and consequently no court proceedings instituted. In an overview of research literature Milne and Bull (2001) draw attention to the fact that people who have learning disabilities are often tested for reliability as witnesses through assessment of what they cannot do rather than that for which they are capable, and they suggest that there is an urgent need for research into this.

Interviewers need to improve their competence in obtaining best evidence from learning disabled witnesses and guidance is offered in a document entitled *Achieving Best Evidence in Criminal Proceedings: Guidance for Vulnerable or Intimidated Witnesses, including Children* (Home Office Consultation Paper *cited by* Cooke 2001). In his article Cooke provides guidance on how to achieve best success in interviewing vulnerable people.

A decade ago an Australian Report Law Reform Commission Publication (LAWLINK NSW2 1996) cited several reasons why police officers may experience difficulty in dealing with people with learning disabilities including their inability to distinguish learning disability from minor substance abuse and mental illness.

It is not surprising that police officers were unable to draw a distinction when, according to McKenzie *et al* (1999), a study of health care and social care staff revealed that only 16% were able to define the three criteria used to define those with a learning disability, which they detailed as:

- significantly sub-average intellectual functioning, with an IQ of approximately 70 or less.
- concurrent deficits or impairments in present adaptive functioning in at least two of the following: communication, self-care, home living, social/interpersonal skills use of community resources, self-direction, functional academic skills, work, leisure, health and safety.
- onset before adulthood.

European policy (Human Rights Act 1998) and government policy (Scottish Executive 2000) has attempted to address the problem of abuse however it is in the practical work situation that change must take place.

The Vulnerable Witnesses (Scotland) Act 2004 was introduced to redress this

injustice yet as recently as March 2007 it was reported that 20 - 50% of men in prison have a specific learning difficulty. Parallel to the introduction of legislation that supports vulnerable witnesses, the UK Parliament Hansard questions and Home Office [*both accessed 11<sup>th</sup> July 2007*], produced guidance for the training of police in line with the Disability Discrimination Act 1995.

Acknowledging the role of nurses and midwives in the protection of clients, the NMC (*accessed 14<sup>th</sup> February 03<sup>3</sup>*) point out that that need will not be met while practitioners are themselves vulnerable to abuse in the workplace. They further suggest that all employers must ensure an environment that is safe, supportive and free from harm. Thus it could be argued that one needs to be free from abuse in the workplace in order to be able to protect others from it. This adds a new dimension to abuse in that staff who failed to protect clients or who are perpetrators of abuse might use workplace abuse as a mitigating factor in their defence.

With regard to core skills and desirable skills of a newly qualified learning disability nurse the National Board for Nursing, Midwifery and Health Visiting for Scotland [NBS] (2000) identified the two that specifically relate to protection. Both are identified as core skills and are as follows:

- be able to build people up so they feel accepted and safe.
- know how to deal with aspects of abuse.

Other core and desirable skills identified by the NBS imply the need for dignified and safe care. The current governing body, the Nursing and Midwifery Council (NMC) have produced various A-Z Advice Sheets addressing safety and public protection *for example* Duty of care (*accessed 07<sup>th</sup> July 2007<sup>1</sup>*) Registrant/client relationships and the prevention of abuse (*accessed 07<sup>th</sup> July 2007<sup>2</sup>*), Risk Management (*accessed 07<sup>th</sup> July 2007<sup>3</sup>*) and Whistle Blowing (*accessed 07<sup>th</sup> July 2007<sup>4</sup>*). Duty of care is defined by the NMC as the 'exercise of skill of an ordinary competent man exercising that particular art'.

The General Social Care Council (2002) introduced a new Code of Practice for Social Care Workers and Employers which was developed by all countries of the United Kingdom describing the standards of conduct and practice within which they should work. In particular one of the standards within the code details that 'As a social care worker, you must promote the independence

of service users while protecting them as far as possible from danger or harm. This includes challenging and reporting dangerous, exploitative discriminatory and abusive practice and reporting unsafe practice of colleagues. Whether or not these standards or those of the NMC result in increased reporting of poor practice of colleagues is yet to be seen. This type of standard has been a feature of nursing codes of practice for many years yet Carter's report indicates that nurses who themselves have been found guilty of abuse have commented that they have seen others abuse patients yet they never reported it (Carter 1999).

Vulnerable people are often subject to bullying and victimization. In a study of bullying and victimization within schools, Veenstra *et al* (2005 ) stated that bullies have been reported to be aggressive, impulsive, hostile, domineering, antisocial, and uncooperative toward peers and to exhibit little anxiety or insecurity. When they are in control, according to Veenstra, bullies feel more secure and less anxious.

In contrast Veenstra *et al* suggest victims exhibit poor psychosocial functioning tending to be more withdrawn, depressed, anxious, cautious, quiet, and insecure than others. Furthermore they suggest that bullying and victimisation are not mutually exclusive with about half of bullies in the school population also claiming to be victims. Whilst this latter claim might be appropriate in general terms it is less likely to have relevance in the context of this study. *For example*, although there is paucity of evidence it is unlikely that people who have severe learning disabilities are bullies on account that they would lack ability to be so calculating. Nevertheless they are often victims of bullying. Language again is an issue here where in the case of people with learning disabilities it is others who confer the 'victim' label based to that person being subjected to bullying, harassment, violence, *etc.* and that person being characterised in a particular way.

The shattering of basic assumptions about the self and the world is central to the process of victimization (Mezey and Robbins 2000). They define victims as people who feel diminished, pushed down, exploited and invaded but they describe it as a transient state in which disequilibrium is followed by a restoration of health and normal functioning - a natural course of recovery is expected.

The organization Freedom to Care (accessed 10<sup>th</sup> October 2006) have described victimization in 5 stages:

- the perception of difference between 'us' and 'them', 'me' and 'him/her' creating an In-group and an Out-Group.
- Those of a manipulative and domineering disposition in the In-Group use the perception of difference to build their own influence and power, demanding obedience and loyalty.
- Once a sufficiently solid situation of leadership/obedience has developed, the idea of harming the Out-Group emerges and is promoted. A preparedness to join in harming the Out-Group will be seen as a test of true loyalty to the In-Group. The victims are now dehumanised by the very fact that others are prepared to harm them - they appear as 'victims', as weak.
- As the number of victimizers grows individuals will be put in a position of 'stand up' or 'stand by' in situations of conflict and disagreement. There is now risk involved in being a dissenter. People say that they will help, but are afraid to. It gradually becomes 'abnormal' and unacceptable to be a dissenter or even a bystander.
- The logical conclusion of the process. The victims are not worthy, not even of life itself. Abuse is normalized, sadism grows, 'victims' are killed (character assassination, job assassination or simply assassination).

### 2.10.3 *Abuse as a clinical perspective*

Within care services terms *such as* physical abuse, financial abuse, emotional abuse, verbal abuse, sexual abuse and neglect are widely accepted as language associated with adult protection, whilst 'lay' terms *such as* assault and battery, harassment and bullying, theft, rape, *etc* would not generally have countenance within those documents or in everyday practice in care settings. Yet in society it is the lay terms that are used unless describing situations involving those in receipt of care. Indeed no personal experience of the aforementioned abuses would ever be described as abuse. Instead it would be described as experienced *that is* slapped, kicked, raped, shouted at, terrorised, *etc*.

Through discussion of Wolfensberger's theory of normalization Smith and Brown (1992 *pp* 88 – 89) suggest that staff 'put on a professional mantle which separates them from their clients/patients sometimes to the extent that they no longer perceive the common humanity between themselves and the people who use their services'. The implications of this are incredibly powerful. They further suggest that this degree of physical separation can lead

to the abuse that all too often characterises institutions.

Sinason (2002 *pp.* 426) wrote of the sexual and physical abuse of children and, drawing some analogy with adults with learning disability, made reference to the language of this experience as follows:

Linguistically, it is worth considering that as part of the medicalising of the experience and the devaluing of children, the term ‘child abuse’ exists rather than ‘child rape’. In a similar way, when adults with learning disabilities are raped, they are also spoken of as abuse victims rather than as victims of the criminal offence of rape. Adult survivors of sexual abuse are referred to as vulnerable adults.

The Law Commission (1995) defines a vulnerable person as an adult over 16 who is unable to protect him or herself against exploitation or significant harm.

In relation to physical abuse Sinason (2002) writes ‘it is worth considering the different impact of terms such as ‘physical abuse’ compared with ‘assault’ or ‘grievous bodily harm’. The medicalising of abuse referred to by Sinason may have led to confusion in the minds of those supporting people with learning disabilities to whom first disclosures might be made.

#### *2.10.4 Abuse as perceived by victims*

In a report entitled ‘Living in Fear’ (MENCAP 1999), the findings of a research study of the views of learning disabled people regarding abuse were reported. It reported that 9 out of 10 people had experienced bullying in the last year with two thirds being bullied on a regular basis and one third being bullied daily or weekly. The respondents in the study referred to ‘kicking, biting, name-calling, teasing, stealing, pushing, threatening, having things thrown at you, being told to leave a building, hitting, being shouted at, swearing, demanding money, hair-pulling, throwing stones, spitting, poking, being punched, being beaten up, having one’s head banged against a wall and racial and sexual harassment’. This makes up a horrid catalogue of abuses that are perpetrated against this group of society.

#### *2.10.5 Abuse within care services*

Mencap (1999) suggest that ‘people with a learning disability face discrimination in all areas of their lives – on public transport, at work, in shops

and leisure centres and even in residential homes and day services’.

In another report entitled *Barriers to Justice* (1997) Mencap provided graphic representation in a case study format of the lack of justice for people who are learning disabled when they write:

‘The recent ‘Longcare’ case in Buckinghamshire revealed a history of systematic sexual, physical and mental abuse against people with learning disability over a 10 year period. .... The total sentence for the three ‘carers’ was 2.5 years’.

Besides Longcare there have been many high profile investigations of abuse of which Borders, Scotland (Scottish Executive 2004b) and Cornwall, England (Healthcare Commission 2006a) are examples identifying similarities and these include poor record keeping, inexperience of staff and lack of training between the Longcare situation and the more recent Cornwall investigation Healthcare Commission (2006b).

Holman (2001) reported on a discourse with solicitor Nicola Harney, who specialises in high value personal injury and clinical negligence actions particularly with people who have learning disabilities in which she states ‘surprisingly, none of the firm’s learning disability cases involve Health Authorities ..... to take a case it often has to come through a relative, advocate or friend; none had come from people using health provision ..... Whilst it may be the case that Health Authority provision is so good that no abuse occurs, any of us who have ever worked within long stay provision will know of the potential for such cases’.

Churchill (1992 *pp* 31 – 32) raises an important point when he poses:

Social workers, trained perhaps in a different tradition [from the hospital or medical model] may reject the current role of the hospitals and yet be compelled to see them as a ‘place of last resort’ for clients for whom they cannot find suitable placements in the community. In this role they may find themselves at odds with their own professional beliefs being driven to use a service they feel is fundamentally inappropriate.

This then raises questions even about the nature of the placement if ethically it is felt to be an inappropriate placement. Yet in 2006 we still see admissions to hospitals being used as a last resort when community services are unable to cope.



MacIntyre (2002), reflecting on his personal experience as a care worker, highlights concerns regarding undervalued and inadequately trained staff and suggests this provides the seeds for abuse in the institutional context.

Reporting his interview with Harney, Holman (2001) wrote that an alternative to prosecution of abusers, many of whom would not have sufficient funds to pay compensation, is for people to make a civil claim against the organisations who employed the abuser and who perhaps offered insufficient training or failed to notice early enough that abuse was taking place. In this case the burden of proof is not as great as that required for criminal prosecution. Harney sees this as a legitimate method of securing compensation for people who have been wronged and points to the vicarious liability of the organisations. She does however caution that, as the claim is against the organisation rather than the abuser the sense of justice can be lessened however another benefit is the opportunity for multiparty abuse actions against organisations.

Within care services employment law for staff sometimes takes precedence over what might seem right and proper procedure when dealing with alleged abuse of vulnerable people. Joyce (2003) wrote of the need to balance the need for adult protection with the need to be a good employer when investigating allegations of abuse against staff.

When an alleged abuse is not proven against a member of staff all records of the allegation are destroyed following completion of the investigation and any subsequent disciplinary hearing. However since the outset of this study there may have been a shift in this regard since advice from the Mental Welfare Commission for Scotland (Appendix 1 letter dated 19<sup>th</sup> April 2002) would indicate that some Healthcare Trusts keep records in a central file.

A centrally held file containing detail of allegations made might go some way to providing learning disabled people with possible corroborative evidence since in Scot's Law the so called Moorov Doctrine enables corroboration if the circumstances are similar in time, character, or circumstance (House of Commons Hansard Written Answers 1996) where one can corroborate the other even in the absence of a second witness. Moreover knowledge that a central record is kept may be enough to dissuade possible abusers from targeting people if they fear that their name may appear in the central record in

a way that might reveal a pattern.

In 2007 the Scottish Executive is consulting on National Standards relating to Healthcare Support Workers in Scotland. If fully adopted following the consultation records will be maintained of those who should not be allowed to work with vulnerable people.

## 2.11 Adult Protection

Adults living within care services have a right to be free from harm. Since the late 1990s local areas have been developing adult protection policy and many areas make those policies available on websites *for example* Kent County Council and Neath and Port Talbot County Council (*both accessed 11/11/06*)

The Appropriate Adult Schemes have been in place for some considerable time to support children and other vulnerable people giving evidence, however their use has been sporadic across the country. According to Lynne Walsh who is an 'Appropriate Adult' in Kingston:

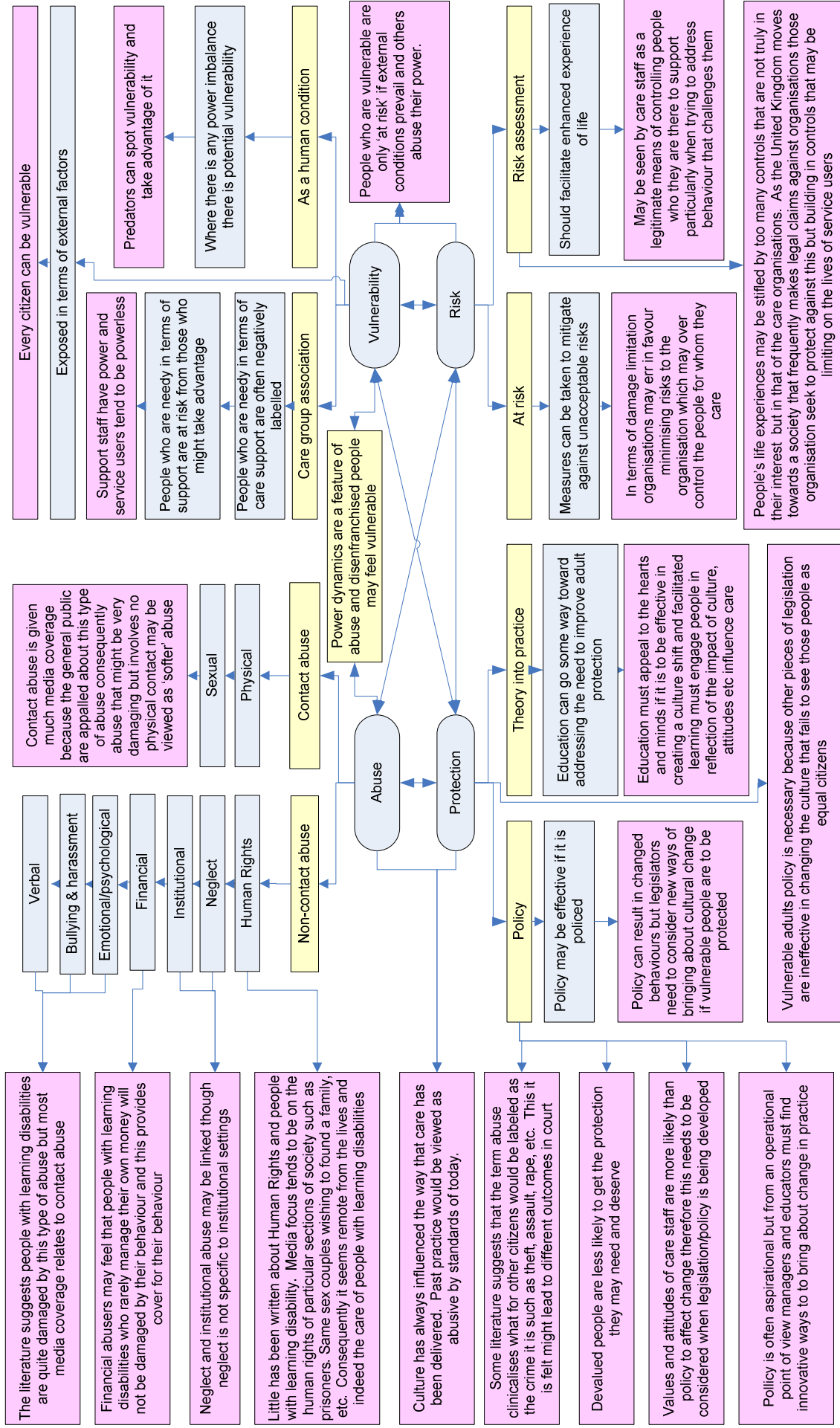
Police officers and other professionals are really diligent, but custody suites are busy places and they can't always notice if a detainee is not quite understanding. We are there to ensure communication is as good as it can be and that interviews are conducted properly and fairly'.

Her use of the term detainee suggests that support of this nature is generally given to those who are accused rather than those who are victims and this is a view shared by Values into Action (2003). During the course of this study issues of all vulnerable witnesses have been considered by the Scottish Executive through consultation (Scottish Executive 2003b) culminating in the introduction of the Vulnerable Witnesses (Scotland) Act 2004.

Power and control are features of all abusive situations and there are power dynamics within care relationships. Therefore, an additional research question within this study will investigate:

To what extent is power a feature of the relationship between people with learning disabilities and paid care workers?

The themes of enquiry in this literature review are represented in a schema (Figure 3) with the broad themes of abuse, vulnerability, risk and protection central in this graphic representation.



22 Figure 3 Schema of literature review

## CHAPTER 3      METHODOLOGY

### 3.1      Introduction

In this chapter all aspects relating to methodology are considered including population and sample, study design, data collection, data handling and data analysis.

The aims and objectives identified in Chapter 1 were concerned with gaining understanding of the views of participants in relation to vulnerability and abuse particularly as they relate to people with learning disabilities. The subsequent literature review (Chapter 2) concluded with a research question concerned with power dynamics between staff carers and those who they support. A qualitative approach therefore was the best approach to gaining that understanding from the perspective of informants.

To address the aforementioned aims, objectives and research question a semi-structured interview schedule (Appendix 2) was developed. The literature review informed the development of the instrument. A parallel study (Taylor and Dodd 2002) utilized a similar tool and this adds to the validity of this choice of approach. Even though that study had a broader focus across care groups the semi-structured interview schedule bore many similarities.

In this qualitative study phenomenological principles as detailed by Byrne (2001) were adopted.

### 3.2      Personal values and their influence on this study

Biases represent the greatest threat to reliability and validity of data and those threats can come from respondents, researchers, methods of data collection, the environment and/or the phenomenon (Parahoo 1997 *pp* 366). Indeed, though not specified by Parahoo, bias could also influence data analysis.

According to Mehra (2002), whilst researcher bias and subjectivity are commonly understood as inevitable and important by most qualitative researchers, beginners in qualitative research are generally not very comfortable with the idea of research that is not value-neutral. She further suggests that a researcher's personal beliefs and values are reflected not only in the choice of methodology and interpretation of findings but also in the choice of a research

topic. Stating that what we believe in determines what we want to study and she argues that it is in the interaction between the researcher and researched that the knowledge is created so the researcher bias enters into the picture even if the researcher tries to stay out of it. Whilst Mehra recognises and almost celebrates the influence of personal beliefs and values, others (*for example* Koch 1995, Paley 1997) in their writings on Husserl's phenomenological reduction make reference to what was described as 'bracketing'.

According to Paley (1997) Husserl thought reduction was necessary if a rigorous foundation for the natural and human sciences was to be established and he states what he (Husserl) refers to phenomenological reduction as a procedure which is associated with the metaphor of 'bracketing'.

He approves Koch's definition of Husserl's phenomenological reduction:

an initial 'suspension of belief' in the 'outer world', either as it is naively seen by an individual in everyday life, or as it is interpreted by philosophers or scientists. The 'reality' of this outer world is neither confirmed nor denied; rather, it is 'bracketed' in an act of phenomenological reduction.

Like Mehra, Cresswell (1994 *pp* 163) points to the importance of making explicit the personal values, assumptions and biases at the outset of the study suggesting that the investigator's contribution to the research setting can be useful and positive rather than detrimental and they are relevant in interpretative research. Drawing on the work of Oiler, Koch (1995) states that the researcher who examine the reasons for selecting a particular phenomenon for study should then take every possible opportunity in the study to elucidate those predispositions and values. In theory 'bracketing', if applied as Husserl intended it should, should improve objectivity, however the researcher cannot be removed from the research at every stage. This is more in keeping with Koch's description of Heidegger's tradition in which it is claimed that human beings cannot be separated from their cultures including historicity of background, pre-understanding, co-constitutionality and interpretation and, as Koch states, 'the world is there before analysis and from the beginning the person is in the world'.

Therefore in acknowledgement of this there is a need to declare something of my personal beliefs and reasons for choice of this subject.

I chose the subject of this study generally because of personal experience of investigations into allegations of abuse toward people who might be deemed vulnerable and more specifically to the different perceptions of abuse expressed during that process and lack of literature and guidance across the range of abuse specific to people with learning disability within the practical setting.

Additionally I felt that much of the underlying reason for people with learning disability not having a voice in this situation, or any other for that matter, amongst other reasons is that they are not viewed as equal citizens. This influenced the literature review, which in turn influenced the choice of direction for the study. In the presentation of the results (Chapter 5), though the quotes of informants are unadulterated, the presentation of the information and the meanings and understanding is influenced by my thinking.

With regard to respondent bias four informants acknowledged the effect personal experience of abuse had on their views. Though others did not specifically acknowledge this it was evident that all respondents drew heavily on personal, family, religious and cultural values. This would also be consistent with Heidegger's view that people are products of the world in which they live as well as influencing their world.

In this study that uses an inductive approach phenomenological principles as detailed by Byrne (2001) were applied as opposed to pure method. Conclusions were drawn and theories generated from the rich context specific data provided by informants.

### 3.3 Population and sample

'Qualitative researchers have never been primarily concerned with how representative their sample is of the total population, seeking instead rich sources of data' (Reed et al 1996). However Reed *et al* suggest that to rely on friends, colleagues, local knowledge or serendipity is haphazard and decidedly unsystematic, but they propose the use of a matrix for the identification of the sample. In this study the following matrix (Table 2) was developed. Though the numbers from each organisation were identified the odd number per organisation meant it was not possible to be definitive within each regarding exact male/female or qualified/unqualified split.

Statutory Sector								Independent Sector							
Local Authority (n = 5)				Health (n = 5)				Private (n = 5)				Voluntary (n = 5)			
Q		U		Q		U		Q		U		Q		U	
M	F	M	F	M	F	M	F	M	F	M	F	M	F	M	F

Table 2 Matrix representing sampling considerations (Q = Qualified, U = Unqualified, M = Male and F = Female)

### 3.3.1 Population

The aim of this study required that the breadth of the learning disability care sector be identified: this defined the population of the study. The population therefore is care staff working within services for people who have learning disabilities living in Grampian.

### 3.3.2 Sample

The care sector falls into one of two main categories; statutory and independent. Health and local authority fall within the former whilst the independent sector comprises the voluntary and private sectors. That being so, a sample was chosen that included those organisations. Much of the client contact is with unqualified staff therefore it was important to include both qualified and unqualified staff in the sample. The term unqualified is used to differentiate between those with a professional social work or nursing registration and those without, although most staff whether qualified or not receive in-house training with many undertaking vocational qualifications.

Since it is reported that more males than females abuse (*for example* Carter 1999 in the UK and the Australian Bureau of Statistics 2005) it was necessary to ensure that account was taken of male as well as female views in this study. Within each type of organisation 5 people were interviewed using a stratified sampling method. Considerations for selecting the sample were:

- organisation agreement
- gender mix
- skill mix of qualified and unqualified staff
- mix of experienced staff and new recruits.

The use of such criteria in the selection of a sample is referred to by Reed et al (1996) as purposive sampling. Coyne (1997) details 15 different strategies for

purposefully selecting information-rich cases but she argues that ‘the underlying principle that is common to all these strategies is selecting information-rich cases (*i.e.* cases that are selected purposefully to fit the study).

The profile of the actual sample (rather than the ideal sample identified in Table 2 above) is best represented as a bar chart (Figure 4) below.

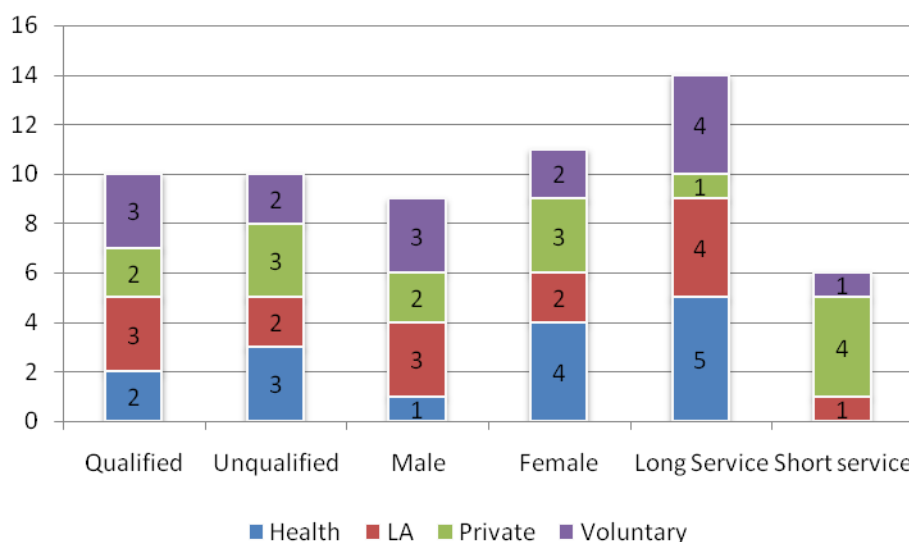


Figure 4 Profile of staff included in the sample

There were five respondents from each of the health, local authority, private and voluntary sectors. Across the 4 sectors there was an even split between qualified and unqualified staff. Initially an assumption was made that the educational backgrounds of the different professional groups would be reflected in the responses to the subject under study. However as the study progressed no discernable difference was detected since several respondents had migrated between the different organisations and acknowledged the influence of experience within the health sector on their thinking.

Eight respondents, who at the time of the interviews were not working in health, had done so previously and reported that their practice was influenced by previous experience and education.

There was a higher proportion of female versus male respondents who were short serving (*i.e.* 18 months or less in service), with 4 out of 11 female respondents being short serving but only 2 of the nine male respondents fitted this criteria. The total sample population numbered 20.



## 3.4 Study design

The aim of this study was to conduct an analysis of vulnerability and its relationship to abuse within learning disability services. This involved garnering the views of care staff within learning disability services. The study design was matched to the nature of the data sought.

According to Cavanagh and Gray (2002) qualitative research is often dismissed by academics where the randomised controlled trial is the 'gold standard' whilst qualitative research suffers from the 'stigma of the small *n*'. The chosen approach for this study provided an opportunity to capture information that a much broader paper based survey might have missed.

### 3.4.1 Study Method

In the semi-structured interview schedule specific questions were identified and this was supplemented with prompts should this have proved necessary. Whilst Robson (1993 *pp* 237) likens questionnaires to interviews he points to important differences:

- in interviews the interviewee can be affected by 'interviewer effect' of which he lists class, ethnic, gender and age differences. No such influence is likely where the respondent completes a questionnaire
- in questionnaires the researcher is ignorant of influences regarding the choice of response whereas in an interview a respondent may (or may be prompted) to elaborate on a particular point.

Nonetheless the possible interviewee bias detailed by Robson, this subject could best be explored through the use of interviews with precautions taken to reduce or report interview bias.

Price (2002) suggests:

'Nurse researchers frequently make use of open interviews in their studies, hoping to understand the private world of respondents, and in particular the ways in which thought and behaviour are connected to each other' (Price 2002).

Nevertheless, Price points out that scant guidance is available on how to translate such goals into specifics of interview technique suggesting that the success of interviews rests on working ethically and understanding the respondents' needs.

In this study both open and closed questions were posed. In keeping with the semi-structured approach detailed by Parahoo (1997 *pp*293 – 295) the questions were predetermined as were the prompts. In some instances interviewees, whilst answering early questions, provided answers to questions posed later in the interview and in those cases the subject matter was not addressed a second time, however all questions were covered with each respondent.

Crowe (1998) cited Denzin and Lincoln when he wrote qualitative research is to study things in their natural settings, attempting to make sense of, or interpret phenomena in terms of the meanings people give to them. In this study an examples of behaviour that might not have been observed outside the natural setting was when an informant, referring to policies for adult protection, rolled her eyes to the place on the shelf where the policy folders were stored.

#### 3.4.2 *Justification for the chosen approach*

The choice of semi-structured interview was reached after exploring the literature relating to vulnerability and abuse. In light of that review it seemed that there was a lack of commonality in the interpretation of those terms. It was felt that the choice of a qualitative approach through use of interviews would provide the best opportunity to ‘use responses of the participant to guide data collection, probing for further information as needed for depth and clarity’ (Sorrell and Redmond 1995), and this did in fact prove to be the case as informants seemed to respond well to positive sounds of encouragement and in many instances elaborated on their answers following such feedback.

### 3.5 Data collection

Initially managers of the organisations were contacted to ascertain their willingness for participation. Following their agreement each was provided with a copy of the letter of invitation to participate (Appendix 3), a Research Subject Information sheet (Appendix 4) and a consent form (Appendix 5). The time required for interviews was discussed and the participating organisations agreed to participants being interviewed in work time. The managers agreed to one hour interviews although they expressed willingness for that to be extended.

Following nomination by the manager of the organisation potential research subjects received from the researcher the letter of invitation to participate in the study, a Research Subject Information sheet and a consent form. They had time

to consider the request before returning the consent form indicating willingness or otherwise to participate in the study. A stamped addressed envelope was provided for the return of consent forms.

Once agreement to participate was reached interviews took place at a mutually agreeable venue of the participants choosing. The approximate duration of the interview was discussed with the participant during the introductory information and where the interview seemed it would run over the agreed 1 hour interviewees were given the opportunity to terminate the interview.

The ladder technique which was used by Price (2002) and which starts off with less probing questions and leads toward more probing questions as the interview progresses is described by him as a technique where the researcher can select questions and responses designed to promote the flow of interesting data, whilst respecting the needs of respondents. This approach was used to develop the interview schedule for this study.

### 3.6 Data handling

The transcription of the two pre-pilot interviews and the two pilot interviews provided necessary practical experience for assessment of the time needed between interviews to prevent the build up of tape recordings which had not been transcribed leading to possible confusion.

To avoid confusion a statement was made giving each a unique number at the start of each recorded interview.

A typist was used for the transcribing of a three interviews. Care was taken in the selection of someone for this task and the typist was informed of the nature of the study so that an informed choice could be made by that person regarding involvement .based on knowledge of the study subject and possible content of interviews. The person was informed of the importance of confidentiality. A further consideration was the accuracy of transcriptions. It emerged that the typist did encounter some difficulty with clarity of tape recordings therefore the researcher who had carried out the interviews transcribed the remaining interview tapes.

Tape recordings were kept in a secure filing cabinet for storage. They will be

destroyed following completion of the study.

Using word processing software the tapes were transcribed. As each interview transcript was completed it was added in sequence so that on completion all interviews were contained in one electronic document. Additionally each transcript was separated into component parts by question so that Question 1 had 20 responses and so on. This provided an opportunity to cross check the data. The volume of data generated in this study was immense and a consideration was given as to whether or not to use a software package such as NVivo for qualitative data analysis. However by the time the transcribing of the interviews was complete there was already an intimate link between the researcher and the data and the themes identified by the researcher and affirmed by the informants. It was therefore decided to proceed with what Jemmott (*accessed 1<sup>st</sup> May 2007*) described as manual, tedious and time consuming methods of data preparation, management and retrieval - integral parts of data analysis in his positive appraisal of the software. He described how he used the software reviewing data documents line by line and developing or applying codes to represent themes, patterns and categories. Whilst this approach to data handling is advocated by Jemmott the manual method employed in this study, albeit more laborious, also involved the categorising of data into themes. To avoid overuse of data the software tools in the word processing package was used to highlight extracts used in the results chapter.

### 3.7 Data analysis

According to Ramprogus (2002) analysis of qualitative data is fraught with pitfalls and problems yet novice researchers continue to pay little attention to the rigour required for such complex data. Robson (1993) cites the work of Miles when he says that qualitative data have been described as an 'attractive nuisance' with the attractiveness of the qualitative research, through the use of words, being undeniable. He describes the nuisance value as the possible problems that a naïve researcher might experience.

Robson (1993) describes analysis of qualitative data as an ongoing process in which the notion of systematic procedure is at its core and it is based on rational argument to interpret empirical evidence. His suggestion that analysis should start as soon as data is collected was adopted in this study and through a process of reflection the data were themed, compared and contrasted. The objective of

the analysis was to address the main aims and objectives and the supplementary questions of this study and to draw conclusions from the evidence.

The matrix (appendix 6) was developed to assist the management of data handling. Miles and Huberman (1994 *pp240*) describe the construction of a matrix as an enjoyable problem solving activity however they draw on their experience with groups with whom they have worked to state that this technique can produce very different types of matrix data depending on the constructor of the matrix but each with its advantages and limitations. They describe matrix development as creative yet systematic and intended for the furtherance of the understanding and meaning of data. In this study the matrix provided an extra tool for checking and cross-checking data across which was generated in all twenty interviews therefore in addition to aiding data handling it was also of benefit for analysis.

More specifically Miles and Huberman (1994) provide greater detail of the qualitative approach. In their chapter on cross-case analysis, such as that employed in this study, Miles and Huberman refer to generalizability. In it they suggest that just adding cases will not help but multiple cases adequately sampled and analyzed carefully can help us answer the 'reasonable; question. Miles and Huberman pose the question 'Do these findings make sense beyond the specific case'?

In this study a multi method approach to analysis has been adopted. Using more than one method in an investigation can have substantial advantages even though it almost inevitably adds to the time investment required (Robson 1993 *pp 290*). Robson asserts that an important benefit of multi methods is in the reduction of inappropriate certainty where researchers are deluded into thinking they have found the 'right' answer and he refers to the advantage that it permits triangulation – 'a method of finding out where something is by getting a 'fix' on it from two or more places. Where the straightforward 'fix' does not apply it does not mean that one set of data is untrue but that the presumed relationship with the triangulation point either does not exist or has to be understood differently. In this study with its focus on personal attitudes of staff there is no right or wrong answer and this is consistent with the views of Lincoln and Guba (1985 *pp 14 – 15*) who assert that basic beliefs can never be proven – in conformity with nature – or declared as false. The broad concepts of

vulnerability and abuse in this study are viewed from the perspective of the informants and presented using themes and case studies.

The themes generated commencing with Interview 1 through Interview 20 and checked for validity (See section 3.8 below) with respective interviewees were copied to a matrix (Appendix 6) on which each interview was coded for its reference to the identified themes. Themes about which there was considerable agreement across interviews were highlighted (pink) and will be reported in keeping with those themes. Some themes generated during early analysis were not addressed in any detail in other interviews (highlighted peach). Whilst those are points which may be of interest for further study in the future, in order to do justice to the evidence for which there was either corroborating support or very strong but differing views a pragmatic decision was reached not to address them further in this study. Therefore no other attempt was made to distil those themes. Finally columns have been highlighted (green) to illustrate the interviews that will be utilised as case studies. Individually they reflect important issues – some from shared perspectives and some from very differing ones - whilst collectively the five address most of the themes identified during the initial analysis (excluding those aforementioned peach highlighted). In Chapter 5 both the case studies and themes are presented. Together they addressed most of the themes generated (Appendix 6) there was no obvious rationale for either to precede the other hence the case studies collectively address more of the themes they are presented first.

All evidence is of some use to the case study researcher: nothing is turned away (Gillham 2000 *pp* 20). Gillham however cautions that the researcher needs to be organised in the management of data since the volume can be great and of variable relevance and one needs to consider multiple sources of evidence for the purpose of cross-referring.

Analysis of the data began with the first interview and continued thereafter thus in the presentation of results, which involve the use of narrative of informants, analysis is a feature.

Cresswell (1994 *pp* 159 - 160) discusses the importance of indicating the forms to be used in qualitative narrative and of those listed the following are utilised in this research:

- Varying the use of long, short and text-embedded quotes.
- Intertwining quotations with (author's) interpretations.
- Using indents to signify informant quotes.

### 3.8 Reliability and Validity

Robson (1993 *pp*70 – 71 and 73) states that the argument is sometimes made that validity depends on reliability so we should focus on validity; the argument being that if we can show that validity is acceptable then, necessarily so is reliability. Young et al (2001 *pp* 31) point out that validity of an instrument is not established through a single study but rather is an accumulative process hence it could be argued that studies based on newly developed tools lack credibility. However, they suggest that each confirmation of validity is like adding a brick to a building and they offer three types of validity;

- content validity.
- criteria-related validity.
- construct validity.

Furthermore it is suggested by Trochim (*Accessed 17th July 2007*),

Some qualitative researchers reject the framework of validity that is commonly accepted in more quantitative research in the social sciences. They reject the basic realist assumption that there is a reality external to our perception of it

He asserts that validity, reliability and objectivity fit more comfortably with quantitative research, whilst different criteria are more relevant in qualitative research (Trochim *Accessed 17th July 2007*) and he suggests 'it doesn't make sense to be concerned with 'truth' or 'falsity' of an observation with respect to an external reality'.

The differences between qualitative and quantitative requirements identified by Trochim are replicated in Table 3 below.

Traditional Criteria for Judging Quantitative Research	Alternative Criteria for Judging Qualitative Research
Internal validity	Credibility
External validity	Transferability
Reliability	Dependability
Objectivity	Confirmability

Table 3      Validity and reliability in qualitative research (Trochim *17th July 2007*)

Credibility involves establishing that the results of qualitative research are credible or believable from the perspective of the research participant (Trochim *Accessed 17th July 2007*). Therefore to ensure credibility within this study the transcripts of the taped interviews were returned to the respective respondents for comments on accuracy and this also provided an opportunity for the participant to check validity of the themes drawn from the data by the researcher. Thus the themes drawn were checked to establish whether or not they matched the intended message provided in the individual's response to the questions posed. It should however be noted that the themes were not a summary of the respondents' comments. Rather they were conclusions drawn from the available information.

Transferability in qualitative research, according to Trochim, is concerned with the degree of generalizability and transferability to other contexts. He places the responsibility for this on the person doing the generalizing suggesting that this can be done by thoroughly describing the research context and the assumptions that were central to the research. Transferability of the research is then the responsibility of the one wishing to use the approach based on the aforementioned context description. The employment context of the informants in this study is shown in the sample information of this chapter whilst context specific information relating to the individual case studies and quotes issuing from the interviews is integrated into the presentation of results.

Reliability, is more appropriate in quantitative research as it is based on assumptions of replicability or repeatability but it is argued that that is based on the premise that we could observe the same thing twice and that 'by definition if we are measuring twice, we are measuring two different things' (Trochim *Accessed 17th July 2007*). In other words, it is certain that one or more variables will have changed even if it is only time. Dependability in contrast relies on the researcher reflecting the ever changing context within which the research occurs and how it affects the research. This can only be done as the research progresses and emerging contextual changes become apparent. In the presentation of case studies drawn from these interviews (Chapter 5) there has been some attempt to present a profile that sets the context of each informant whilst recognizing his/her right to anonymity. The overall sample detailed earlier in this chapter presents contextual information whilst changes in legislation, policy and practice impacting on the study are reflected in the



literature review and discussed in Chapters 6

Confirmability ‘refers to the degree to which the results could be confirmed or corroborated by others’ and Trochim (*Accessed 17th July 2007*) suggests two strategies both of which had relevance for this study:

- The researcher documents the procedures for checking and re-checking the data throughout the study
- Another researcher can take a ‘devil’s advocate’ role with respect to the results and this process can be documented with any potential biases highlighted.

The process of returning the tape transcripts to the respondents addressed the first of those two points. By so doing the respondents were able to comment on both the accuracy of the transcripts and on the appropriateness of the themes drawn identified in analysis. Should the latter have been contested account could have been taken of the respondents’ comments and the revision returned for further comment however this did not prove necessary. A letter (Appendix 7) and proforma (Appendix 8) was sent to each respondent along with the transcript asking that they indicate whether or not they felt the transcript truly reflected the interview and the themes drawn seemed reasonable based on the content of the interview. This approach elicited a 100% positive response.

### 3.9 Pilot study

Robson (1993 *pp 164*) suggests that empirical research should involve pilot testing as this provides opportunity for assessment of time, effort and resources. However, he states that:

Whereas a strong case can be made for every experiment or survey being thoroughly piloted, there are aspects of case study research which can make piloting both more difficult to set up and, fortunately less crucially important.

He further suggests that in some cases it can be difficult on account that no sensible equivalent might be found for the pilot. In this study the interview schedule was tested in a region of Grampian that would not be included in the full study. Interviews were conducted in accordance with the plan for the full study. Two people were invited and agreed participate. They were identified in the same way as that identified for the full study: the first approach was to the line manager. The pilot participants were each provided with the introductory letter, subject information sheet and consent form, the latter of which was

signed by both participants. The set questions were addressed in the order planned for the full study and at the outset of each pilot interview the participants were informed of the purpose of the pilot and advised at the outset that additional questions about the pilot would be addressed at the end. I sought and received approval from the participants to return their respective transcribed interviews. This served a dual function: a check of accuracy of the transcription and the opportunity to comment on the themes drawn from the interview content.

Typing of the tape recorded pilot interviews was done by me and this provided an opportunity for me to gauge the amount of time required between interviews in order to keep pace. As I was unskilled in audio-typing it took approximately 8 hours to transcribe each tape. The time required for transcription was little considerable hence it was necessary to pace the interview timing taking account of this requirement.

A useful lesson was learned during the pilot in that conducting two interviews in one day resulted in an almost overwhelming workload to achieve a fairly rapid return of the transcripts. It also proved more difficult to recall gestures made by each respondent in emphasis of points. Field notes were not taken as it was felt this would detract from the flow of the interview.

The quality of the recordings was good but occasional noises from outside the interview venue rendered some words inaudible. Nevertheless the main content was clear and the overall quality good when confirmed by the participants.

### 3.10 The ever changing context of the study

One respondent suffered bullying, one sexual abuse, two had experienced issues relating to abuse of power recently in the work setting and one implied physical and sexual abuse however this latter was not made explicit. Within the context of the interviews none of the respondents who reported such experiences offered any mitigating comments in support of their abusers. For each it was a very personal experience. Though all respondents in the study stated that their views of this subject were based on long standing values and beliefs, it cannot be ruled out that the respondents who had experienced abuse of some form or other might not have responded differently but for those very personal experiences. Every person is a product of his/her life experiences and the life experience of all respondents will have shaped their views adding to the

richness of the data.

### 3.11 Conclusion

This chapter has detailed the method for the study. With regard to the sample both the ideal and the actual sample were detailed in this chapter and this is discussed in Chapter 7. The chapter concludes by putting the research in context of time, changing environment etc.

## CHAPTER 4 ETHICS

### 4.1 Introduction

In this chapter consideration is given to ethical considerations made in development and implementation of the research. In particular the focus is on ethical principles, consent, safety and security of data and ethical issues pertinent to this research study.

An application (Appendix 9) was made for ethical approval for the study. Additional measures were requested by the ethics committee of NHS Grampian and, following correspondence regarding this (Appendix 10) approval was given. A further application was made to the ethics committee of The Robert Gordon University.

As a manager within NHS services for adults who have learning disabilities I have in recent years carried out investigations into allegations of abuse. Though not broadcast, that involvement was known within care services and this may have reassured prospective respondents knowing that those difficult issues had been managed or it may have caused them anxiety.

The possibility for potential participants to feel compromised by my line management position within the NHS learning disability service was a consideration. The letter inviting participation and the research information sheet indicated that a decision not to participate would not in any way affect their employment. As the health participants were approached first by another manager in the organisation they had the opportunity to decline at an early stage even before the point of nomination. Thereafter, as with all other participants they had the opportunity to withdraw at any time.

At the outset of the study senior managers within my employing authority, NHS Grampian, were aware of the nature of the investigation and were satisfied that any disclosure of abuse within current services would be brought to their attention as would be the case for any other participating organisation.

Due to the nature of the study there was a possibility that disclosures of abuse might be made. Those disclosures could have been of a personal nature or relating to practices within care settings. The research information sheet detailed

these as possible risks of participation and it was indicated that:

- If through the study they disclosed information relating to abuse in the care setting not previously shared with anyone I would support you to take further action.
- If through exploration of the subject you wished to access professional counselling I would assist them in the quest to find a suitable person.

No-one sought support to report abuse within their respective line management structures and though some views expressed were indicative of current practice that is disrespectful information relating to overt and deliberate abuse was dated.

Disclosures of respondents personal experience of abuse was a relevant factor. It was decided that if respondents became distressed during the interview, it could be terminated. Though disclosures were made no participant decided to terminate the interview although the opportunity was there. Disclosures of an unlawful nature where clients were at continued risk were not made so no further action was necessary in this regard.

Because of the sensitive nature of this study, approval from senior management was sought to use my workplace mailing address for correspondence (Appendix 11) and approval was given (Appendix 12).

## 4.2 Ethical principles

According to Parahoo (1997 *pp* 78) there are ethical issues at every stage of the research process and he argues that there are ethical considerations, even regarding whether or not a topic should be researched. Notwithstanding, he suggests that basing practice solely on custom and practice is to deny patients the best possible care and he goes on to query whether or not it could be unethical not to examine one's practice.

Robson (1993 *pp* 30) defines the difference between ethics and morals. Whilst both are concerned with right and wrong each has nuances that separate one from the other. Whilst the former is concerned with general principles of what one ought to do the latter is concerned with whether or not a specific act is consistent with accepted notions of right and wrong.

Robson (1993 *pp* 29) questions whether participants should be misled as to the true nature of a study, or if they should be faced with situations that cause them stress or anxiety. Robson argues that this should not be so however he advises

consideration of cost and benefit *that is* cost in terms of stress and anxiety to participants and benefit of knowledge gained or service improvement, then there may be justification for the approach. Nevertheless, he cautions that careful consideration of this is necessary as he queries 'How is our right to know balanced against the participant's right to privacy, dignity and self determination' and he challenges the investigator's the right to act as judge and jury.

Parahoo (1997 *pp* 78 – 79) describes six principles: beneficence, non-maleficence, fidelity, justice, veracity and confidentiality. He has synthesised those six into four which will be used in consideration of this study; the right not to be harmed, the right of full disclosure, the right of self determination and the right to privacy, anonymity and confidentiality. Ramcharan and Cutcliffe (2001), in considering social research ethics discourse, identify similar principles which they state have appeared widely in a series of codes of ethics. However they assert that apart from being unenforceable and with no sanctions on perpetrators of unethical work such codes have other difficulties. One of those difficulties relates to the code that proposes no harm (avoiding maleficence) to subjects where, according to Ramcharan and Cutcliffe questions still arise about what exactly constitutes harm.

The ethics of health and medical research differ somewhat from social research and Ramcharan and Cutcliffe (2001) conclude that 'Given that social research is not a treatment nor physically invasive, at what point is a person an individual in their own right and one who can choose for themselves whether to become involved in or to withdraw from a research project.

#### *4.2.1 Right not to be harmed*

This study, with its focus on abuse of vulnerable adults, had the potential to cause some distress for participants in that consideration of issues relating to abuse is never very palatable. Further, in sampling no information was available regarding abusive situations that prospective participants might have experienced either in the past or at the time of the interview. Nor was there advance notice if any participant had experienced feelings of vulnerability in his/her life.

Specifically, the research is concerned with the perceptions of staff rather than their practice and in that respect each respondent was an expert of his/her own views. An assumption of the research is that the values and beliefs each holds

shapes the person he/she is. Consequently, this has an affect on care given. The values one holds are as much part of the individual as physical characteristics of the body but it is the values and attitudes held that impact upon how individuals see the world and their place in the world and that of others. Probing such deep held beliefs relating to vulnerability and abuse could prove difficult for some respondents therefore the interviews needed to be conducted in such a way as to elicit the information but be sensitive in the manner in which the subject was explored.

If necessary, as Parahoo suggests ( RCN 1993 *as cited in* Parahoo1997 *pp* 78), interviews would have been terminated if as according to Parahoo ‘research subjects entrust themselves to the researcher, who has an obligation to safeguard them and their welfare’. In his considerations of interview techniques Price (2002) offers a cautionary note when he points out that researchers who use interviews cannot predict how strangers (participants) might receive specific questions and he reminds that questions about action and behaviour *such as* ‘what have you been doing lately?’ is less invasive than those about knowledge *such as* ‘what made you do/think that?’ The latter, according to Price, is less invasive than questions about beliefs and values *such as* ‘what do you believe should happen then?’ This study was very concerned with beliefs and values therefore great care was necessary in the introductory phase and in the framing of the questions.

#### 4.2.2 *Right of full disclosure*

Prospective participants were made aware of the nature of the study and invited to participate. In the interview setting I opened the session with a brief description of the research and its purpose and enquired of participants whether they had any queries before finally deciding whether to participate in the study.

Respondents were given the opportunity to see and comment on the accuracy of the transcribed interview. This had the added benefit of checking that I had heard correctly what had been said.

#### 4.2.3 *Right of self-determination*

People who were approached were free to decline to participate at the first approach and at any point thereafter. Should they have decided to withdraw after the interview had commenced they were assured that no data from the interview

would be retained and used within the study. The purpose of the study was transparent and information was not withheld from prospective participants in order that they reached a decision about participation in full knowledge of the facts. Therefore all interviews were carried out by informed consent.

No coercion was used to persuade people to participate.

#### 4.2.4 *Right to privacy, anonymity and confidentiality*

Respondents were made aware of the following:

- All identifying data of the individual and his/her place of work would be removed from transcribed interviews.
- People who would see the content of interviews would be limited to me and my research supervisory team. An audio typist was used for 3 interviews and the need for strictest confidentiality was stressed. A further consideration was the possible impact of the data on this person.
- People choosing to withdraw after commencing an interview were assured that no record of the interview would be kept.
- At the conclusion of the research all data would be destroyed.

The computer on which the data would be stored is a stand alone PC that is password protected. No one else had access to the data.

### 4.3 Conclusion

In this chapter all ethical aspects of the research were considered and measures taken to meet the requirements of the Grampian Research Ethics Committee. The chapter also detailed the measures taken to ensure that ethical principles were applied to this research.



## CHAPTER 5 RESULTS

### 5.1 Introduction

In this chapter the results of the study are presented in two sections: case studies and themes. As detailed in Chapter 3 the themes were generated from the interviews. A matrix (Appendix 6) was developed for reference purposes. This was used to identify the cases (vertically on the matrix) that addressed many of the themes. Five were used for case study. The matrix was also used to identify themes that were common across most interviews (horizontally on the matrix).

Throughout the case studies and themes sections of this chapter the individual themes being reported are identified using bullet points.

The stories offered in the case studies illustrate in rich detail individual perspectives. However, whilst tonal inflection and physical gestures are lost in this representation, use of the verbatim accounts better demonstrates the message rather than purely an interpretation of those views.

Respondents were best able to convey their thoughts on this difficult subject through recount of experiences from their pasts. The Society for Storytelling (accessed 8<sup>th</sup> November 2005) offer the following description:

Storytelling predates the written word, people have been telling stories for as long as we have had speech. Even after the invention of writing only a minority had access to the written word. Stories passed from lips to ears, changing as each teller forgot things, or deliberately left them out, and replaced them with their own inventions. This is the 'oral tradition'. Even now we think in narrative and tell anecdotes, urban myths and personal stories almost without realising it. Stories are learned image by image, rather than word by word, and are retold from the heart in gatherings with friends or in public performance. Each telling will be different as the teller chooses their words to suit their audience. This is oral storytelling.

People use story telling as a means of making sense of their world and it adds colour to what might otherwise amount to a rather bland string of words. According to Crowe (1998 *pp* 339):

Words do not operate as external signs of internal meaning for the individual but rather, as a pre-determined system for the allocation of meaning; they are not reflections of an external reality but expressions of group convention.

Many of the informants in this study carefully used language as a means to

illustrate what they intended when they described the subjects of this study: vulnerability and abuse. They emphasised this through use of body language and story telling.

Coelho (2007) spoke of storytelling as ‘a common language cultures have’ and he suggested that adults place low value on stories considering this to be associated with childhood. However he argued that we should always ‘accept the child in us’ otherwise we lose the ability to be amazed by new information. He emphasised this by saying that it is often messages conveyed in stories by nannies or primary school teachers that most influence and shape the people we become. It is argued that the stories in the results chapter (Chapter 5) of this study enhance the quality of the data. Those stories are presented throughout to illustrate specific points and are framed for emphasis.

In case study presentations of selected interviews verbatim accounts of informants are used. Each informant is given a pseudonym and his/her contribution is shown in *italics*. To differentiate, during two way dialogues, the interviewer’s comments though not named are shown [bracketed using normal font]. Within the quotations of informants [*italics are bracketed*] where a word has been inserted to explain the topic under discussion rather than use a long quotation. An example of this is where the informant says *it* at a point following earlier mention of policy – in this instance it would appear as *it [policy]*. Elsewhere, *for example* around references, (brackets) are used.

Defining the context of each case study and the use of verbatim accounts improves integrity of the research and the purpose of the subsequent presentation of results and analysis must be to ‘faithfully reflect in summary and organised form’ what has been found (Gillham 2000 *pp* 25 - 26). Gillham however warns that research data is unlikely to be tidy and may appear contradictory and he advises against feeling a need to ‘clean up’ the picture to make it acceptable.

Five case studies are presented:

Case Study 1	Marcus
Case Study 2	April
Case Study 3	Julian
Case Study 4	May
Case Study 5	June

After the presentation of case studies there follows analysis of identified themes.

Many of the conventions used in the case studies section *for example* framing stories, use of italics, etc. were also used in the themes section. A similar presentational style using both long and short quotes was utilised. However unlike the case studies, which were person specific, the themes utilised data from the entire sample.

As detailed in Chapter 3, the twenty interviews generated a considerable amount of data. Initial analysis of that data, prior to development of the matrix, was done using only the themes generated from each successive interview and summarised in a schema (Figure 5 overleaf) similar in style to that used in Chapter 2.

Although not all content from all of the interviews could be utilised because of volume the case studies and themes presented following the schema are representative of that original analysis.

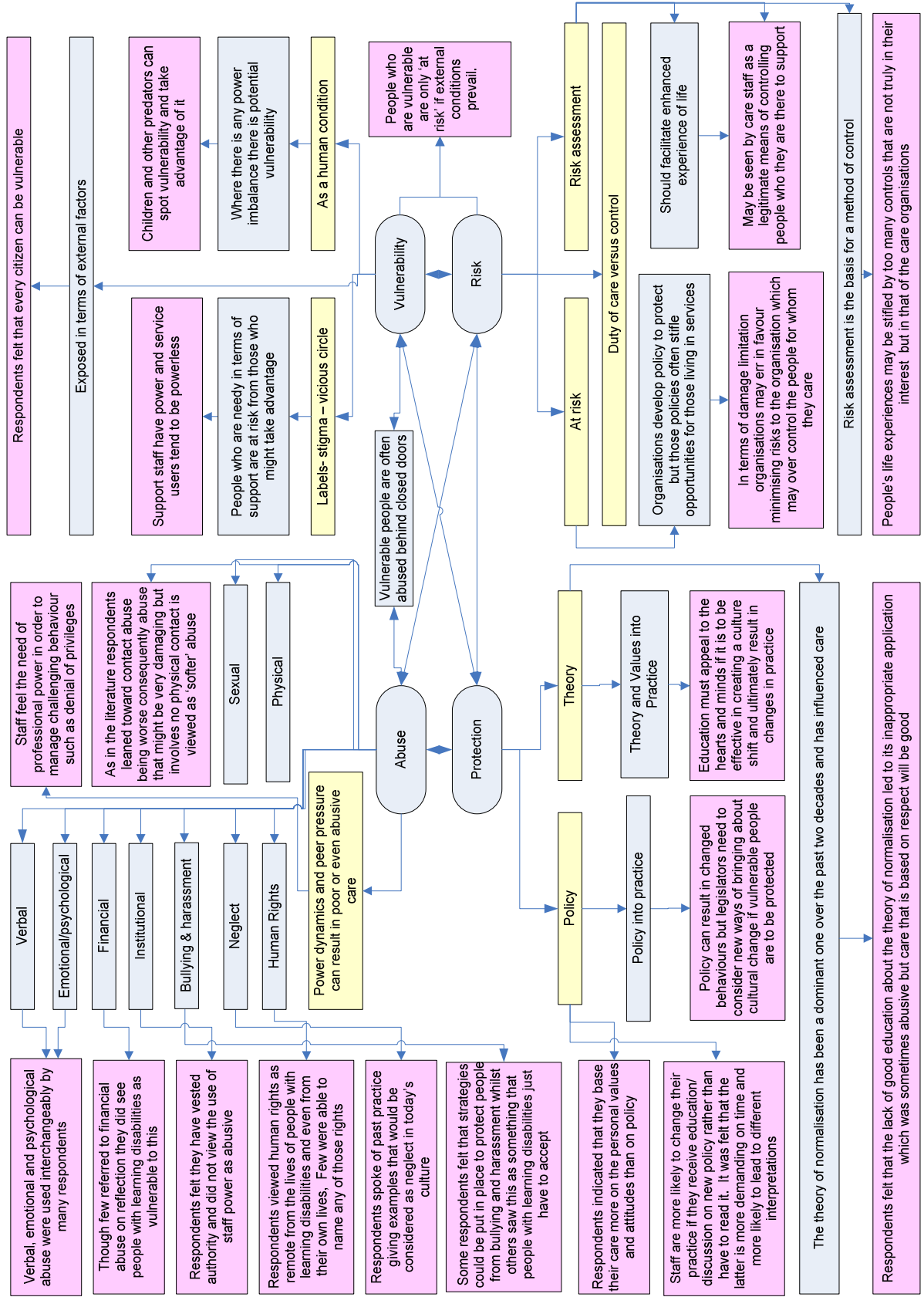


Figure 5 Schema of findings from all 20 interviews

## Case Study 1 - Marcus

Marcus has worked within care services for people with learning disabilities for 18 months. Prior to this he studied various subjects at university unrelated to care. In relation to his employment within the care sector Marcus said:

*I think people that are working with people with learning disabilities should be trained more because I haven't been trained that much, you know I'm not a qualified nurse and there is often a gap between people like me who have just come from university doing [non-health related subjects] which is nothing to do with learning difficulties [mmhm] and people who have been trained as nurses.*

- Staff are often educated about how to speak with people but they are seldom advised how to deal with offensive behaviour of others i.e. turn the other cheek or challenge
- It is not easy to speak out about negative practice.

Confidence associated with increased knowledge was a feature of this case. Knowledge was also seen as power and it was clear that with increased knowledge along with personal values it is possible to speak out against bad practice.

Marcus underplayed the contribution he could make in his position based on his life experience, respecting instead the experience and knowledge of longer serving individuals who had undergone formal education in care. As Marcus works more often on a one-to-one basis with only one individual and only occasionally in a group living situation it often proves difficult for him to be released for training whilst still continuing care and this is not likely to be peculiar to his employer. Therefore there is a need for adequate early education perhaps at induction for all new recruits. Supervision of staff is also an important feature of staff support and development. He recognised this himself when he said:

*Em ..... my experience of the service that I work in is that there isn't enough supervision from people higher up - seniors and management - so people will sort of form their own values in the absence of a superior.*

Later he returned to this theme and, though he came across as an individual who considered how his actions and that of colleagues affect care and support, he nevertheless felt the need of a theoretical framework.

Although Marcus was working in the independent sector he referred on more than one occasion to the importance of nurse education.

*My knowledge is far less and I'm far less confident and I think the more training people get the better and the more consistent and the more supervision and there's an absence of that ..... and its kind of stressful to work ..... I feel that I'm working as a nurse but I'm not remotely qualified. I'm just some goon who's come off the street and had maybe 4 days training. [Mhmm - you're maybe underplaying your own abilities] yes, but just to hedge your bets you want to be trained enough. I think I do OK. [mmhm].*

Despite the fact that he states his *own values are pretty fixed* and influence the way in which he provides care and support, he nevertheless felt the need of additional training especially given the challenges that he feels staff face.

*.... but I've seen it with other people. It's kind of stressful to be working with people who are very vulnerable and to not feel that you're maybe knowledgeable enough to help them all the time. You help them in other ways by being nice to them.*

Whilst discussing the need for sound education and guidance, Marcus expressed his discomfort about the language of learning disability when he spoke of an interaction with a child when he felt inadequate:

*I had a child asking what was wrong with somebody once, [mmhm] when I was pushing somebody in a wheelchair [mmhm] and the child was asking what was wrong, but I didn't say anything because I didn't know what would be the right thing to say, I just said he was blind I think [mmhm] and that was it. [Was that a young person?] Pretty young, about 8ish [So just out of interest they were asking, rather than.....?] Yes, the person was unusual for a child who hasn't seen many people with learning difficulties or blind. [Mmhm OK.]*

As he was unsure how to respond to the natural curiosity of the child perhaps due to his awareness of the stigma associated with the label of learning disability he chose to deny it preferring instead the physical disability label that is less berated in society. Although it is not possible to illustrate Marcus's tone of voice here, the manner in which he spoke was kindly but conveyed his discomfort in explaining the person was learning disabled or even why a wheelchair was necessary. Although he spoke throughout the interview about his lack of training he did nevertheless refer in a rather sketchy manner to training provided by his employers:

*I've had some training – courses like client protection. There was another course that we did – something to do with abuse and that sort of thing.*

Marcus spoke of the service principles and contrasted that with how in practice

there is lack of adherence to them:

*The official line with the people that I work for - the official sort of 'this is what we intend to do' and 'this is how people should be treated', and you know the words of the manager .. 'we should never force somebody to do anything' sometimes contrasts with 'while the cats away the mice will play', not horrible vicious abuse, [mmhm] but a culture of maybe, like passive neglect, and contempt. [mmhm, mmhm]. It sounds terrible, but I've never really discussed this before. [mmhm].*

- Manipulation is used to 'encourage' people to do as staff wish.

Manipulation is a different way of misusing power and it is used to 'encourage' people to do as staff wish although in some instances it is seen as a method of persuasion. Marcus spoke of the service principles and contrasted that with how in practice there is lack of adherence to them:

*The kind of stuff that I've seen is just an attitude of treating service users like children and trying to get them to do something, trying to get them to eat when they don't want to, and getting angry with them when there is not reason to get angry with them because they don't really know what they are doing that is annoying people.*

Manipulation and coercion are misguidedly used sometimes with good intention as is illustrated in the following rather long extract with staff believing that the most important thing is nourishment however that is achieved.

*That was something that came up at a meeting not long ago. It was to do with one of our service users and this person sometimes doesn't want to eat her tea, and has in the past been persuaded to eat her tea by means of - holding up the thing that they actually want - which is a drink - and saying 'you won't get this drink until you've eaten up your dinner'. And one of the seniors said that it shouldn't have happened ... You wouldn't treat an adult like that. So that has happened.*

When asked if he had a personal view on this he said,

*My personal view is that sometimes that particular person is treated badly because it's expected that person should be eating and that person isn't at all gaunt or malnourished. It happens a lot where the person just doesn't want to eat so it's a source of irritation to the employees who are like 'Oh no - not eating again', and it seems arbitrary - there's no pattern - like they ate this thing the other day, but they don't want it today ..... Its like they've (clients) got their own set of rules or maybe just the mood they're in. They just want to get to the drink and they're not thinking 'If I don't eat I'll die.*

Frustration of staff is evident in this claim although Marcus did introduce this by saying that the person was *treated badly*. Superiority is not something that many

staff would acknowledge in themselves and yet somehow Marcus felt that the negativity of being so can be countered by good intentions when he said:

*Yes sometimes I find myself ... and I know other people do it ... they do talk to them in what might be construed as a patronising way but done in a friendly way - but on one of the courses we did it was said that that kind of thing maybe isn't advisable, talking down to somebody as if they were a child.*

When probed further on this issue Marcus conveyed that even if told to treat adults as adults, in reality this proved difficult when he responded in dialogue:

*[Did you feel that you got reasonable approaches offered then when you were told that wasn't perhaps an acceptable way?] Em ..... [Did you get offered any alternatives?] Not exactly alternatives, just suggested that you talk to somebody as you would talk to somebody who didn't have learning difficulties. But you do fall into the trap. I do it all the time. [mmhm?] ..... In a benign way.*

Without actually saying so, his comments were indicative of an attitude that adults with learning disabilities are children trapped in an adult bodies and that despite the advice of seniors there is a natural inclination to revert easily to treating people in a childlike way. Later however he did refer to childishness. Marcus spoke of this in relation to lack of equality of citizenship for people with learning disability and his expressed view showed an honesty about his experience that would be contrary to the teachings of his organisation when he said:

*It's hard to say ..... No I don't think they would be regarded as an equal. The people that we work with - their learning difficulties are so severe that it's hard to think of them as ..... even though you like them and you are friendly with them. I was going back to the childlike thing - the people that we work with - because their learning disabilities are so severe they are often regarded as child-like and maybe implicitly not equal, [mmhm, mmhm] but I'm not sure. Em - a lot of the time they would be treated just like anybody else - sort of as a pal sort of thing.*

Although he did not convey superiority and there was warmth in the way he spoke of those he supported, implicit in his comments is the implication that even within friendship there are inequalities.

Viewing people as different results in behaviours toward them based on that perceived difference and Marcus drew on his experience to illustrate this.



*... someone at work was describing one of the service users, to that user's sister and saying that ... that he looked 'cute' and the actual service user was in his late 40s, and the sister sort of mildly took offence - not badly - but she did say 'You know he is whatever age he is - 48'. [mmhm]. And I think maybe to the service users themselves it might not make any difference but I suppose you are treating them with the respect that you would treat them if they hadn't been born with the affliction that they have got.*

Power over colleagues also leads to bad practice as Marcus illustrated.

*People (staff) will copy each other's behaviour and I've seen new employees being indoctrinated into a kind of quiet contempt for service users, [mmhm] and a lot of the time also I've seen people being mentally abused and being treated with contempt and what I've often found is if you witness that kind of thing you can often clam up and within the service each individual will have their own unique way of treating the service users. There will be a general official line but each individual will have their own way of treating them. [mmhm?]. Some will be very kind and patient, others will be more aggressive in the care that they are giving.*

But on occasions practice falls below that which is condoned or even accepted and even though it is never easy Marcus explained how he took time to consider what had happened before taking action.

*... one time somebody was being quite loud - service user was being quite loud and one of the employees was being loud back sarcastically and I found myself and the other person that was on basically clammed up but that was on a Friday and by the Sunday I phoned up my manager and said 'such and such has happened'. There was no physical abuse or anything. It was just like out of order behaviour [mmhm] and the manager had a word with the person in question.*

- Vulnerability is not necessarily associated with care groups.
- Staff can protect people from risk but they cannot take away vulnerability.

Vulnerability, according to Marcus, was due to disabilities for example *if they cannot speak, if they have a lack of mobility*, due to labels for example *if they've got learning difficulties of some kind, whether that be autism or Down's Syndrome, blindness and lack of understanding*. An example of this is *the fact that they have learning difficulties and they can't communicate to somebody if they have been abused, or know that most people would regard it as wrong*. Despite his clarity whilst defining his view of vulnerability that people with 'learning difficulties' and 'Down's Syndrome' would be vulnerable, as the interview progressed his view

regarding labels changed slightly:

*It doesn't matter if they are labelled as vulnerable. It doesn't matter what anybody labels somebody as they are either in a position of vulnerability or they are not, I think.*

- Vulnerability is easily spotted though not easily defined.

When the notion of risk was introduced a further dimension required consideration and Marcus became less able to distinguish whether or how much they differed.

*I'm not sure, maybe at risk is something slightly different, I think potentially vulnerable, but not actually vulnerable, [mmhm. Ok. So if you were describing risk then, what would you say was the situation if a person was at risk, as opposed to vulnerable?]. I'm not that sure, I can't quite figure at risk, I don't know if that's worse than vulnerable.*

However in relation to the risks that people with learning disabilities may face he thought,

*Yes [they have reason to feel vulnerable] but I don't know how vulnerable they necessarily feel. We would call them vulnerable but maybe they themselves wouldn't have that concept except at certain times. [mmhm] I think a lot of people with learning disabilities - this is a horrible generalisation, [mmhm] live in the moment. They don't have the same values as people without learning disabilities.*

- People who have learning disabilities do not always realise they have been abused.

According to Marcus people with learning disabilities may not feel as others on account of limited understanding.

*Somebody's learning disabilities might be so severe that they wouldn't, [pause], have any understanding of what abuse is taking place, or they wouldn't have the same values as people without learning disabilities [mmhm] though the hurt might be equal.*

- Care practice that is done with good intention or that does not apparently offend the person on the receiving end is not abuse.

However although he felt the emotional suffering may be different he felt the sensation of pain may be the same for people with learning disabilities and others. Therefore if abuse is not perceived as such by the individual there is a risk that this does provide some cover for those who might abuse – somehow people with learning disability are viewed as less human, less feeling and less knowing. Marcus drew on his own experiences since coming into care and though he did not claim to have seen what he would have considered gross abuse he reflected that he

had observed behaviours that he considered abusive. In terms of whether he had a 'cut off' point that he would find unacceptable he stated, *I think all of them are bad, but I've seen like verbal and mental abuse, and roughness, you know happening myself*; however those went unreported. Consequently if recognised as abusive but not reported it is likely that the behaviour will continue almost as custom and practice. He reflected:

*I was thinking about just, maybe active abuse, like being verbally abusive to somebody or being physically rough with them or more like passive abuse ..... like for example, sitting watching TV, blaring loudly which a service user doesn't want if they are blind or putting on music which they don't want to hear rather than their music - their CD [mmhm. Am I picking you up correctly then - that it would be the deliberate act of that rather than the ignorance of having the TV on loudly?] yeah, but maybe not realising that you are doing it if it's become a habit - like if its become the norm for people to do that in the place that you work at.*

Marcus used terms *verbal abusive* and *being a bit lippy* interchangeably. Despite his reference to *being physically rough with them* by his own admission he had never observed or been aware of anyone being *physically abused or sexually abused* thus it might be inferred that he did not see physical roughness in the same light as physical abuse.

His notion of severity of abuse was also apparent in relation to abuse of power: power in this context therefore is seen as abuse in itself rather than a feature of all abuse. In his consideration of abusive situations he described a more passive abuse of power when he described a scenario familiar to him that resulted in staff only doing what was essential for people.

*Limited staff and becoming creatures of habit, you know, going into work and just feeding and watering them and just not taking them out for a walk and not going out in the van [mmhm] just sort of containment and habit.*

Marcus was very thoughtful and paused several times when considering whether any type of abuse is worse than the others:

*I can't think of one that would be worse than another. Sexual is the first one, but ..... [mmhm?] ..... All of them, you could think of all of them being equal. Like if somebody is neglected for 30 years - that is just as bad as being verbally abused for a month.*

This presents a dilemma since within the umbrella term 'abuse' some types of abuse are viewed as worse than others but within each there may be a perception of

grades of severity. Despite his expression that they were 'equal' he nevertheless named sexual abuse thereby reducing the impression of parity. Furthermore, he introduced a notion that implied a less severe abuse (neglect) over a long period may be as bad as a worse one (verbal abuse) over a shorter time span thus in that short discourse he inadvertently ranked three with neglect being at the lesser end, verbal abuse being more serious and sexual abuse being at the severe end of the scale.

He concluded *from what I've seen I would imagine there is a lot of mental abuse and a lot of the stuff of unpleasant documentary in lots of care places. .... I'm sure there's a lot of fodder for fly-on-the-wall documentaries all round the world.* On this note he said *I've seen - sort of - not nastiness but you can often get something pretty ugly and something very nice in the same day.*

## Case Study 2 - April

April entered a career in learning disability nursing in the 1980s when she *was influenced to go into it when I was doing my general training and was quite disenchanted with the sort of em – em tidy beds and rules.* Even in her early career when nursing was very much dictated by conventions she was something of a free-spirit, feeling that the learning disability nursing might suit her natural style rather than the more restrictive rule based nursing in the general field. During her interview April often drew on examples of practice from her past experience to illustrate particular points.

Within health April had varied experiences. She described a long and varied service that included positions at different levels in the organisation before moving to employment within the independent care sector.

She completed her nurse training in the United Kingdom but not in Scotland moved to another UK country before moving to Scotland. Although the legislation and policy of different countries was different she felt there were many similarities in care across the countries in which she worked.

Outside of her paid employment she has other related interests as she describes:

*Apart from that I am interested in and involved in drama with all types of groups so I've worked with children and adults and people with learning difficulty and elderly and that's me!*

- The way in which staff work with people who have learning disability is based on mental age rather than actual age.

Early in the interview April introduced the concept of respect and respectful practice. However it was in relation to disrespectful practice in the way in which staff speak to or speak of adults with learning disability that she offered examples:

*Em – well ... people get quite a lot of training around this before they start or certainly at the very early stages but even though you speak to the people about the importance of respect and not labelling and not infantilising people you still find that obviously some staff have been working with people with learning disabilities for a long time and those things are kind of ingrained and you get people calling adults the girls, the boys, [mmhm] poor souls [mmhm] people giving people their whole title so it's a bit like again..... childlike.*

She illustrated this last point by saying,

*..... so somebody might say 'Hello [first name, last name]' instead of*

*just 'Hello [first name] and you know - it would be ..... as you might say to a little child so people do tend to use that although sometimes if that's how that person responds and they like that and it works well for them then it's OK*

According to April people talk down to them [people with learning disabilities] and don't listen to what they are saying. She also felt that they are subjugated by regimes in care establishments where care staff used their power and people with learning disabilities knew their place and that once they have learned that behaviour it is difficult to change.

*One of the things that really strikes me about people with learning disabilities – they want to please [mmhm] and that comes from – some people say that that is a kind of childlike quality that children like to please. Well I don't agree. I have children of my own and they were far more able to be assertive and speak out because that was the environment they were brought up in [mmhm] that they were able to speak ..... where they're dependent on people that they have such a big influence on that person's day and how they're made to feel and there are retributions, mainly psychological, but people are left feeling 'I'd better keep in with them' you know [mmhm] and I think that that's really sad [mmhm Yes it is].*

- When normalisation is imposed on people we deny them the right to choose for themselves.

It was not only in the terms of address that April had concerns regarding lack of respect. She spoke in an impassioned way about what she saw as misapplication of normalisation principles and those of social role valorisation.

*Em age appropriateness is another of my things that gets to me a bit ..... Is that somebody took that concept [normalisation] completely out of hand and decided, you know, that there was 1000 teddy bears burnt on fires as people took age appropriateness ..... you're being very disrespectful if you infantilise people if you keep them as a child and don't help somebody to reach their potential if you don't – again inequality – you're not looking at somebody as another adult – you're deciding that you are the grown-up and they are the child.*

She spoke of the misapplication of normalisation theory when she stated:

*I think age appropriateness as a concept wasn't looked at like that at all – it was more 'Burn the toys. Burn the teddies' [mmhm] you know 'Burn his best jumper with the bear on even if he loves it' because he should really have something with an Addidas logo on it [laugh] [laugh] [Oh I know].*

She was describing realism where adults sometimes choose to have possessions or to do things generally associated with childhood. However, the mindless

application of the aforementioned normalisation theories, through the staff interpretation, saw people denied real choice. Instead, if choice was made available, it was limited to choices associated with adulthood. It was not the act of destroying those possessions itself that distressed her but the destructive misapplication of the theory and the consequences to the individual resultant from precious things being taken away.

*The problem with childish things is if the staff member is buying them because they have decided that's what level they're at and therefore that's what they should have rather than if the person really does have an interest in a doll or a teddy and they want that. What I'm saying is I would be quite happy to burn a room of teddy bears [laugh] that staff had just decided looked bonny and they were really quite cute seeing this 30 year old woman was quite doll-like so let's get her Polly Pocket bedcovers and that's a different thing.*

Emphasising the exception of using childlike terms of reference only if they are preferred by the individual, April suggested that individuals should be addressed in a manner that pleases them and not in the way chosen by staff. In the use of terminology, she also felt that divisions were unnecessarily created by staff who were in a position to do so. She said,

*I think people also get spoken to as a 'them and us'- them being different from us, the staff [mmhm. In what way would they do that?]  
Eh – let me think – as in talking in front of people and they might say 'They don't mind' or 'They cant hear' or ....*

By considering people as different an environment is created where they can be treated differently. When the perceived difference is that people with learning disabilities are inferior to the staff who support them the power imbalance is a catalyst for control of the environment including the labelling practices adopted. As seen in April's earlier comment, this happens despite training and education early in employment and her use of the word *ingrained* implies deep rooted values and attitudes. Those attitudes, she opined, were so strongly held that *they do try to broaden their thinking but I do think their natural reaction is to think in a parental way*. She also said *that's got a lot to do with how dependent somebody is so the more dependent they [people with learning disabilities] are the more likely they [staff] are to view them as children*. Although training is provided for staff as has been demonstrated in case study 1 Marcus did not feel equipped to deal with the disparaging way in which people are spoken to or about. Like Marcus, April provided some of those disparaging labels such as *dafties*. The values and attitudes

of the person applying the labels influence labelling. Respectful behaviours are expected of staff including the manner in which they speak to and about people with learning disabilities.

*Yeah – well ‘right to respect’ – don’t we just hammer that down everybody’s throat. ....it’s a very difficult one because you are dealing with people’s value base and maybe they’re not very respectful people to start with.*

Yet, as April points out, education alone cannot change this and on occasions more punitive measures need to be imposed.

*I feel that respect is a kind of old fashioned concept so it’s getting more difficult than it ever was although in services we are managing to hammer that we will have this – you might not want to do this but we’ll have this and if we see you being otherwise we are going to pull you up for it [mmhm] but that’s different than a cultural change.*

Rather worryingly April felt that, with the increasing focus on respect, people had just become more sophisticated in presenting a veneer of respect rather than changing their practice based on any real passion. Thus it can be deduced from her comments that no amount of insistence on the part of managers will make people respectful if they do not feel a sense of respect but managers may insist on particular behaviours. Drawing on her early experience in nursing April explained why she had greater concerns about the calculated veneer than the open bad practice.

*You know it always bothered me more if I saw somebody in a very difficult time with the service, and this is more from my days at the hospital, if I saw somebody being a bit inappropriate and disrespectful while they were trying to handle a situation – I always felt happy with that because I could see they were being open they were thinking it was OK and so they were doing it.*

By contrast April had greater concern about what she saw as covert management of challenging behaviour.

*... somebody who disappeared with somebody, took them off down the back and things went awfully quiet – that would worry me more [mmhm] if I didn’t see somebody’s practice – if somebody was very careful always to have a veneer of respect and politeness but you know sometimes you would discover that that hadn’t been the case [mmhm] so I’d rather see somebody warts and all rather than a veneer of respect.*

At this stage in the interview I suggested that it was curious that in the past people



were more respectful in society in general yet today we have more legislation and policy stating the need for respect in care services. However respect is a rather ill-defined concept:

*Yeah I think they were more respectful in society but before the respect was missing in services and it was a bit scary [mmhm mmhm] you know on the abuse front and maybe people, you know - being very cynical - maybe they have just got better at hiding it [mmhm].*

Where respect is lacking from those who are employed to provide support and the power and control is with them the situation is ripe for manipulation of people who are dependent to do as the staff wish.

*[pensive] .... I think from my experience in the service it would be for the people that I work with it's more the erosion of self – of self esteem, of making people dependent and not feel .... able and empowered and, you know, being spoken down to and being – you know ‘when they’re on shift I’ve got to do this or else ...’ and that kind of thing is completely shaping somebody else’s behaviour by your own actions – I would think it’s mainly psychological and you know people cutting people down to size, making them feel needy and not worthy sort of thing*

Like Marcus (Case Study 1) April cited examples of how one or more staff members act against the wishes of people they support but to meet their own agenda. Whilst she felt this was sometimes done through ignorance April cited a rather more calculated example.

*So that kind of thing you will get where you get 2 care workers and one doesn’t want to go swimming and so they go ‘Oh they don’t really enjoy it’ or whatever and it really is about their need and not about the service user. I think that definitely happens [mmhm].*

April drew on her early experience in nursing to illustrate her concerns regarding denial as a means of managing behaviour and although she referred to earlier times where dietary intake was managed through a process of bribing the individual with something he/she desired more. Yet as can be seen in Marcus’s comments the practice of bribing people is not yet eradicated.

*Denial of privileges – you picked a big one for me cause it’s something people just thought –when I started my training that was something you did – it was recognised practice. People didn’t get to do things, they didn’t get food they didn’t get to go places and certainly ‘If you don’t eat your dinner you won’t get your pudding’ ..... and that isn’t respectful. There’s no equality there. That is definitely saying ‘ We are telling you that this is what’s going to happen and you will do this and if you don’t we will do this’ There is nothing respectful about that.*

- Some colleagues collude in the use of unacceptable strategies to meet their own agendas.
- Manipulation is used to ‘encourage’ people to do as staff wish.
- It is not easy to speak out about negative practice.

Management of behaviour that challenges services has for long been the focus of attention of single professions and also within multi-disciplinary groups with some viewing use of sanctions for adults as degrading and disrespectful. However even within multi-disciplinary teams there can be discord with positions of superiority either being perceived or displayed by some professions.

*I know there's a huge power and psychology, you know, what they say often gets pushed through [mmhm] And they have a lot of power and that's scary – I mean how scary would it be than if you thought your doctor was going to make the difference between you getting out of here or not [mmhm] and whether you know, you would get to keep your blanket or whatever so I think it has to be multi-disciplinary and it has to be consensus.*

The power imbalance between professionals and those they support was evident in her remark however April also spoke of the power relationships within the multi-disciplinary team.

*Talk about balance of power within the multi-disciplinary team can be difficult because, you know professionals fear one professional more and so maybe their points get ...[voice tails off]..... So it's very difficult when they come up with one of those programmes where the focus is on 'Yeah we're doing this and we're all signed up to it and it's for this person and this reason' rather than it's one professionals idea of coping with something.*

Although much attention has been given to empowerment as it relates to people with learning disabilities April's comments demonstrate that the balance of power within multi-disciplinary teams also requires attention. Indeed by failing to speak out against controlling behaviour of those who are perceived to hold the power in decisions about care there is a degree of collusion with which some staff would feel discomfort but nevertheless feel powerless to change.

- Dependence, powerlessness and vulnerability are linked.
- There is a balance between duty of care and risk assessment.
- Power is a feature of abuse.

*How would I decide somebody was vulnerable? .... Well it's one of the things that we look at – what makes somebody vulnerable - and people*

*have lots of different ideas and a lot of it is around being dependent and if you have to depend on people or a service then there may be a power imbalance because if you are relying on another person to fulfil a particular need for you then a perception might be that they have the power [mmhm] so I think if you depend on somebody for something then that makes you vulnerable [mmhm OK that's helpful].*

- Vulnerability is not necessarily associated with care groups.
- The vulnerability label can be conferred on another.

She felt that people are not necessarily vulnerable just because they are labelled in a particular way however she had to use particular categories in defining what she meant.

- Vulnerability is not necessarily associated with care groups.

Because she associates vulnerability strongly with the dependency and power within relationships rather than with how the individual feels it can be reasoned that the 'vulnerable' label can be bestowed on another person thus, although she said that she did not feel the care group label necessarily means people are vulnerable she nevertheless categorised those who might be vulnerable.

*I think it's something else – it's not the [care group] label – I mean for example –I'm thinking all children are vulnerable [You think they are?] I think they are yeah – I think children are vulnerable by nature of their maturity and understanding of concepts, their dependence on people and I suppose as they grow older then they become less vulnerable. Also things that make you less vulnerable are your sort of status and em your ability to learn and you know look after yourself and obviously children don't have that -. [Mmhm] ..... so maybe some people have a vulnerability and then there are people being completely vulnerable [mmhm mmhm] so it's a little bit of a difficult one.*

- A person may feel vulnerable but will only be 'at risk' where external factors come into play.

The concept of immaturity April speaks of is an interesting one since some would consider this as childishness. Nonetheless, since introduction of social role valorisation theory, people resist association of adults with any connotations of childishness seeing it as non-politically correct even though analogies are often made including the content of April's preceding comment.

Neediness on the part of any individual creates a power imbalance and where there is possibility of exploitation vulnerability may co-exist. Certainly in the view of April the two are linked though as seen above she felt that risk related more to

external factors in the form of abuse whilst vulnerability related to internal factors such as neediness.

*..... vulnerability used for people who are frail and dependent or dependent because they have needs – they rely on others to support them etc and children because of the maturity etc.*

Though she set out her view that the terms ‘vulnerable’ and ‘at risk’ are different April’s description nevertheless was of a continuum where the label ‘at risk’ was of much greater concern. She offered this view from a professional stance whilst from the perspective of a person with learning disability the feeling of vulnerability might be very unpleasant even though the individual might not appreciate he/she is at risk.

She then went on to describe a situation where vulnerability exists there is potential for abuse inferring thus that even if it is difficult to describe it is easy to detect. In contrast ‘at risk’ was more clearly defined by her when she said *that label always seems to be something very serious – I mean you tend to hear at risk – sexual abuse, physical abuse and you tend to think of vulnerability as a society kind of thing.* Her difficulty with definition is evident in the following comment

*Em and I suppose they are at risk of people abusing that vulnerability so I suppose I am kind of contradicting myself here because yes when you hear the term at risk you tend to – I immediately think of abuse [mmhm] as in physical, sexual, big – you know not subtle but you know something very – fairly serious. But I think anyone who’s got a vulnerability is at risk at subtle or not so subtle abuse of that vulnerability [mmhm That’s fine].*

At this point we laughed together as she reflected on how difficult it was to articulate the difference in a meaningful way saying *This is not going to be easy for you to transcribe [laugh].*

- Risk taking is a feature of everyday life.

Duty of care is linked to patient safety and in principle should be a positive concept however as is seen in her next comment April felt that staff viewed duty of care to be risk averse.

*people are very tense about duty of care and frightened about risk, risk, risk and people coming and going as they please and if you look at their vulnerability – there’s a big world out there and you know how people take advantage of them etc so it’s really settling staff down about what is duty of care and why do we do risk assessment – we don’t risk assess*

*people out of their liberty [mmhm]*

On the issue of risk assessment she commented:

*I used to feel that risk assessment was a way to stop people doing things. It felt like that to me. The way that we look at things – the way I try to get people to look at things here is that risk assessment is a way of trying to get people to do things [mmhm] ..... but it is scary.*

In a frank comment she pointed out that some even deliberately misinterpret the concept to impose their own will on a particular situation.

*I think one of our duty of care is to support people both within our principles and guidelines and within the law but some will abuse that and take away somebody's liberty but we usually then dress it up in the fact that it's because we can't keep them safe – we have no guarantees – you know what I mean? [mmhm] But I've seen people deliberately use duty of care to curtail somebody's liberty or to draw them in or whatever so .....*

Speaking of vulnerability April referred to the personal values and the attitudes held by individual staff and how an old adage uttered by staff would not necessarily ensure good and safe practice when she said,

*It's really hits home to me all the time that people think that the sorta best rule of thumb to work with people is to treat people as you would like to be treated yourself [mmhm mmhm] I think that's fundamentally flawed because I don't think people do – I don't think people treat other people as well as they would treat themselves [mmhm mmhm].*

She illustrated this point with an example from her recent practice.

*A chap has just paid £1700 for a new chair and within a week it's ripped at each side because they've been bashing it through the door getting it in and out. Now my question to them was 'If you just got a piece of kit that was worth £1700 for your own house would you – you would not be bashing it around like this' and all the staff in that project have been trained and have nodded their heads and joined in the conversation 'Yes we must protect people's things and treat people like you would want to be treated yourself but I know they wouldn't do that with their own furniture so although the words come out of their mouth it doesn't then develop into their practice.*

- Staff can protect people from risk but they cannot take away vulnerability.

Respect and respectful practice was a key theme throughout this entire interview and it was clear that April believed that if all staff were genuinely respectful of those they support then issues of vulnerability and risk would be greatly reduced and standards of care improved.

*The other flaw with that is, you know, a varying standard so it can leave people very vulnerable because some people wouldn't mind somebody borrowing their stuff ..... if they can't give their permission then we shouldn't be doing that*

According to April people are generally more vulnerable from those with whom they have a relationship (either familial or within a paid care setting) and who they know well with 'stranger danger' being less likely. *You are more likely to be murdered or attacked by somebody you know.* This must be an invidious position for anyone who understands the position but feels powerless to escape and who has to continue to rely on those who do such things.

- Lack of education leaves staff/carers at risk of adopting an approach inconsistent with the principles of the organisation

April spoke of the challenge of ensuring that theory finds its way into practice in a way that improves services.

*They learn the policies, they find out what it's about. We audit that they've got the gist of it but then putting that into their practice doesn't necessarily flow as you think it would [mmhm] because it's about their basic values and attitudes towards something.*

Whilst Marcus (Case study 1) felt that education as well as direct supervision by seniors would result in change, with her considerable experience April realised that even where training and education is provided it does not necessarily translate into changed practice. Yet in the care sector which is hierarchical in nature there are too few managers with too great a span of responsibility to provide the degree of supervision implied by Marcus.

- Abuse, particularly bullying and harassment, is seen as part of the lot of people with learning disabilities
- Personal experience influences the way that care staff view different types of abuse

Personal experience affects the views of everyone and as April said *for some people it [abuse] might be family as with all of us. Some of us might have – in society they may be an abusive family.* In relationships where abuse takes place she described *some imbalance of strength or ... I don't suppose it's always a strength thing, it could be because you have nowhere else to go or there will be some circumstance .....* So clearly for some staff their view of what constitutes abuse will be influenced by personal experience of it but it may not be consistent with the views of those who they support.

Professional experience, whether that is good or bad, also influences the way in which people care. April related a story from her early experience of nursing in the 1980s and clearly she had remembered much of the detail of what was clearly a distressing situation. It was apparent from the manner in which she spoke that it has had an impact on the way in which she supports people some 20 years later.

*I know from my early days that people did use physical abuse. I think I told you the story about the woman who went into the kitchen and stole some sugar and you know she was very, very you know severely learning disabled – she had a severe learning disability and the ward sister had 2 nursing assistants and they spooned 2 pounds of sugar down her throat. That was awful – I mean I was there and it was an absolutely awful thing to see – but then you would often see people getting a push and pull and a shove and a threat [mmhm] and certainly once I was a staff nurse and the charge nurse I worked with there clipped them around the head in a kind of very open kind of way – you know? – he didn't even try and hide it*

Power imbalance is the condition most likely to result in abuse. April was quite specific in her interpretation of power.

*..... and I think the one that people don't think about too much when they are thinking about vulnerable people is the abuse of power in that they have the power to do something for somebody and they don't, and that's a form of abuse [mmhm] so if they see something that isn't right and they don't do something about that – they don't stop somebody else abusing somebody for example then that is also abuse [mmhm] and people don't – I don't think they see that so much and also if you can do something to make someone's life better and enhance it and develop it etc and you don't then that's an abuse of power.*

As can be seen from her comments April felt that some care staff may not consider their behaviour abusive if they have not acted therefore abuse was linked by her to intent. However with regard to power she felt that those who can convey their wishes using any means are not completely powerless even though on a scale of 1 – 10, with 10 representing all power with staff, she did indicate a relatively disenfranchised position.

*I think if you can shout and demand and communicate and maybe in some aggressive way then you are showing you have some power .... It might not be with the best grace but you can shape how things are but on the other hand there's no point in shouting out what you want if nobody's listening to what you are saying [mmhm] .... also people have – some people have family support fighting their corner and I would say on a daily basis probably a low 3.*

Of concern here is the notion that to assert any particular position people need to *communicate in some aggressive way* which is a 'double edged sword' since to

assert a particular position in this way invariably then attracts a ‘challenging’ label. They are even powerless to say they do not want another person in their beds as April explained,

*One of the things that’s very sad is that for years it’s been expected that if you are in the hospital with other people with learning disability or in a service or whatever that being abused by other people with learning disability is par for the course [mmhm] so if somebody with a learning disability beats you up and and you’ve got a learning disability then that is seen as ‘well that’s what happens ....’ If somebody’s sexually abusing you know – that’s just what happens.*

Regrettably this abuse is seen as part of the lot of people with learning disabilities living within paid care settings.

- The Human Rights Act is viewed as remote from care.

Finally, on the issue of Human Rights April expressed a view that was consistent with many other respondents in this study. She felt that this legislation seemed remote to care settings.

*I think it’s [Human Rights Act] quite a difficult one to translate [mmhm] I mean we go over Human Rights Act with people but I don’t think it - it’s not real enough for people. Do you know what I mean? [mmhm] .... I think people think the human rights act is for people who are being tortured in other countries etc .... I mean we talk in human rights about things that em – em what’s the word? ..... it’s not belittle ..... I’ve lost it ..... [degrade?] Mmhm degrade – I think that’s a very real possibility in the services we work in but I don’t think people – it would jump to people’s mind that that is an abuse of human rights.*

April illustrated this with a powerful example from her early experience, at a time after which the European Convention on Human Rights had been adopted.

*One of the worst things I saw was somebody who had been very violent in his time – very, very violent and he had hurt a lot of staff in his time and he had gender issues and wanted to be called a woman’s name. He wanted to be known as Auntie [Mary] and his name was [name] and if you didn’t call him Auntie [Mary] he would beat you to a pulp basically. He had been a very aggressive man and by the end of my training he had deteriorated quite a lot and he had got into his 50s and he had got advanced aging and he was moved to a ward with a lot of old people who were frail and he was frail and he couldn’t hit anybody any more and I can see him now sitting on the toilet and the Sister of the ward saying ‘Come on [name]. Hurry up’ and he was begging her ‘Auntie [Mary], Auntie [Mary]’ and she – I mean I feel quite upset about it still – and she was saying ‘your name is [name] you’re not Auntie [Mary]’ and he was going ‘Auntie [Mary], Auntie [Mary]’ and he was so distressed and she was going ‘Aye and what are you going to do about it? You can’t hit us any more can you?’ ..... and I just ... it was just .... torture ..... it was horrible!*



### Case Study 3 - Julian

Having experienced residential care through school work experience, Julian decided on a career as a social worker. Having completed an *Honours Degree in Applied Social Studies leading to a Diploma in Social Work* he took up his first position as a qualified social worker and during his various experiences he encountered people with learning disabilities who he described as offenders. This experience strongly influenced the way in which he viewed the subjects of this study.

Reflecting on his education, knowledge or experience of vulnerability and abuse he said *I'm trying to think back over the things I did at university maybe related a bit about abuse but I can't think of anything that would be related to abuse.*

Risk and duty of care were linked for most respondents. Julian spoke of this several times throughout the interview on occasions offering examples of the dilemmas faced by staff. One such example was offered.

*I think there has to be limitations where the door is kind of locked for somebody that has – that suffers from epilepsy – I've worked in residential services where there was a policy that the door had to be locked [mmhm] due to an incident happening a few years ago where they had – clients and service users could come and go because at the end of the day it was their house and their community [mmhm] they could go out to the garden, they could do whatever, go to the car or whatever and visit their neighbour but again that changed when somebody had epilepsy and they went outside the door and had a seizure on the road and was knocked down [mmhm] so the result of that was that there had to be a latch on the door to that particular person.*

In this scenario the measure taken by staff ensured the safety of the individual and consequently safety for the organisation however this was achieved by denying her liberty. With regard to this he said *I'm all for liberty in the sense that it is helping people with learning disabilities to do what they want in the community* but he qualified this by saying *but I do recognise that there are limitations to that and I think the aim of that is to give not too much limitations and stop them doing what they want.* Indeed the act of locking the door limited the freedom of all householders with whom the lady shared. Many people who have learning disabilities but suffer from epilepsy live in the community and do not have similar limitations placed on them in the way that staff felt they could do in the situation

described.

Julian also considered duty of care in a broader sense when he felt staff had a duty of care to those who are on a waiting list to receive a service when he explained,

*.... if clients don't come for certain period of time – we do – we are quite harsh in the sense that if there's other people on the waiting list [mmhm] so we've got a kind of informal rule that if you don't come within 4 times to a particular group – 4 in a stretch and there's no particular reason for it we do ask them to leave the group.*

- Staff can protect people from risk but they cannot take away vulnerability.
- Staff need to take measures to protect people from risks.

In response to a question regarding his definitions of risk and vulnerability Julian suggested.

*Eh ..... good question [laugh] [laugh] ..... I think vulnerability is something that somebody hasn't got a voice to so somebody's vulnerable but maybe a risk assessment could be helping that person not be vulnerable..... I think they do kind of work hand in hand but if you get the risk done and highlighted it would stop the vulnerability happening ... to a certain degree. It wouldn't stamp it out completely [mmhm] I think that's how I would [voice tails off] They are different yeah [mmhm OK].*

In this description vulnerability was described in an active sense - *it would stop the vulnerability happening*. It is easy therefore to see that with this notion of vulnerability it might be felt that people could be made safer with their vulnerability reduced. Unlike April (Case Study 2) who saw vulnerability as a condition of the individual resultant from power imbalance Julian felt that by carrying out risk assessment measures could be put in place to eliminate or reduce vulnerability. In the absence of clear guidance from his employer regarding a definition of vulnerability Marcus' (Case Study 1) position was that vulnerability was due to inability to understand or communicate concerns however he saw risk and vulnerability as similar although risk was seen as greater. To an extent April also shared this view.

From a perspective of working with offenders Julian saw risk mainly in terms of society risk in that he considered the consequences in relation to individuals for whom no risk assessment was in place.

*There are guidelines and policies that we have to work under and risk*

*assessments and stuff like that [mmhm] we would need to carry out – so I would presume there would be a policy about putting a schedule offender with learning disability into a work environment where there's children or there's vulnerable adults [mmhm] and I have to follow a procedure where there is a risk assessment, a health and safety and a social assessment. There is procedures and policies to ensure that I do my utmost to make sure that that person will not put anyone at risk including themselves.*

In this view it emerges that rarely are individuals vulnerable and exploiting vulnerability at the same time although Julian did acknowledge that an individual might also be placing him/herself at risk. He detailed a real dilemma with which he had been challenged and the soul searching through which he had gone. At no point did he make reference to supports available to him whilst dealing with such challenges.

*I've got a client that I know that em is HIV positive therefore they know they're HIV positive but they are sexually kind of active and it's actually making them aware like 'Look you need to maybe tell the partners or actually wear protection all the time [mmhm] so I find that kind of difficult. Part of me would want to say 'No don't have sex for the rest of your life because you've got this kind of disease [mmhm] but that's not for me to say just because they've got HIV they have got the right at the end of the day to have sex but again it's just limiting the risk [mmhm] you know that that person is putting to himself and to other people so ..... [mmhm that's an interesting point] It's really difficult. I've struggled with that issue because the first issue – my first reaction was 'Don't have sex, don't have sex' It's just 'Live your life the way you are but don't put anybody at risk' [mmhm] They have got a learning disability but they've got to understand what HIV is and what it can do to them and what it could do to other people if they did have sexual intercourse without protection [mmhm] so yeah there is a dilemma [Yes I can see that - mmhm - I think we're often tested with these sorts of issues] Yes you don't think about it until something like that happens.*

- Vulnerability is easily spotted though not easily defined.

Although like others Julian experienced some difficulty defining vulnerability he nevertheless felt that it could easily be spotted as he said *staff or anybody on the street could take advantage of that person* and he felt that *if they [people with learning disabilities] couldn't do that [voice their concerns], that would be a major vulnerability to themselves [voice tails off]*.

Although Julian did not feel that people labelled within particular care groups necessarily also carry the vulnerable label however he did nevertheless feel that the vulnerability label could be applied to individuals within those groups subject to

certain conditions being evident – *it depends on their situation – it's depends what's involved with them, it depends where they stay and there's so many different factors.* He felt that some people are more likely to be vulnerable on account of *not be[ing] attached to a social worker department, living in isolation, etc* and he claimed *a lot of people that we get through now could've had learning disabilities all their life but not been seeing anybody for 30 years but yet being taken advantage of.* He referred to a situation with which he has been familiar where the main support has been provided by parents however he felt that the absence of support from professionals has resulted in difficult situations.

*I suppose we have a lot of emotional abuse which could come from parents who are kind of stopping their child who has got a learning disability getting on in life. They feel they should maybe leave school and go to a day centre and that's what they do because they've got a learning disability [mmhm] so sometimes I feel it is emotional abuse that they're actually saying to their child ' You can't do this and you can't do that' [mmhm] It's like well they can do that so stop telling your child that they can't do anything other than go to a day centre – they can work, they can earn money, they can lead a normal life like anybody else [mmhm] – eh – so I think there is that bracket of emotional abuse that we do come across quite a lot.*

In this situation Julian described this type of behaviour by family members as abusive whilst the family members would presumably not agree with this believing that they were acting in the best interest of the individual.

Julian used the terms vulnerability and risk interchangeably in the following comment when he stated *I think the issues of vulnerability have always been there but as I say at the start there were risks that I was unaware of that kind of I don't think other people would be aware of.* He provided an example from practice that he felt illustrated this point.

*The new direct payments CHIP and PIN – we had a situation recently when people were taken off to the post office and opening their accounts and what was happening was people were stealing their cards and the PIN numbers they were given so people were actually withdrawing people's pensions [mmhm] withdrawing their DLA, withdrawing their income support and then going back to the house and just giving them £10 and then that client was not telling the care staff what was happening.*

In this regard he felt that he was supported by other team members and explained how this operates in practice *I actually feel that it is a support for me to go back to*

*the team I am in just now and actually make a presentation on that saying this is an actual risk that I never thought of with this particular person – has anybody else?* He went on to explain *that's my way personally to kind of update the team and to refresh the team of risk assessments of the vulnerability that they might have in different situations.* Risk assessments are reviewed and refreshed 6 monthly 'cause we have been caught out in a few situations. Vulnerability was linked with lack of maturity (April – Case study 2), lack of understanding (April – Case study 2 and Marcus – Case Study 1), poor communication skills (Marcus – Case Study 1).

- When normalisation is imposed on people we deny them the right to choose for themselves.

Julian spoke of an instance when an individual using his service wanted to carry along items that might be associated with childhood as comforters. Staff were sensitive of the individual need and, whilst this might have been considered unacceptable in the early days of application of normalization theory, by the early 2000s staff were becoming more sensitive of individual need.

*We do have somebody that comes along with – I think they call it 'a blankie' something they've had as a child [mmhm] and it's something they're very attached to [mmhm] I think as long as it doesn't get in the way of them enjoying the service we provide – for example the swimming group and obviously they can't go into the pool with their blankie which was the issue we came across [mmhm] we kind of compromised in that we normally get the council bus to this pool in Tullos and we don't have a problem with them coming with the blankie ..... [mmhm] so we knew that they would really struggle without having that blankie with them in that particular room so we got round that by having the blankie on the wall or on the seat where that person could see it but at the same time enjoy that activity*

Talking of the individual's right to enjoy a normal life Julian said *I think there's a lot of ignorance behind disability and it still as a society – I don't know how that's going to change but I think it is getting better.* He linked labelling and stigma with ignorance in society and although he felt some progress has been made in redressing this he reflected *Reading studies when I was at university even the terminology - the handicapped kind of – all these words that were used – I think that's changed in the last years and I'm sure it will change in the next 20 years so it's going in the right direction. There's just that stigma attached to it – that label that people with learning disability can't do normal things [mmhm OK].*

- The Human Rights Act is viewed as remote from care.

Abuse of human rights seems remote from everyday practice in a way that other policies are not. Perhaps human rights are not seen as relevant to people who have learning disabilities indeed there may be ignorance of this legislation in general terms rather than in its application. Julian said *I think this is a new thing that I'm certainly not aware of – I think that issue needs to be brushed up on by a lot of the professionals after this came in – I think it was a couple of years ago now.* This interview was conducted in 2003 by which time the Convention of Human Rights had been in existence for more than 50 years and some 5 years after the Act had been endorsed in the UK through the Human Rights Act 1998 and the Scotland Act 1998. He added *I wouldn't classify it [infringement of human rights] in my professionalism just now as abuse. I could see the possibility of it being classified as abuse but I certainly – I would need to brush up on that before I would classify it as abuse.*

Speaking of the challenges that staff face with some people who use services Julian said *Monday morning is a difficult time for them because it's getting back into the routine and the rules and regulations that they have to abide by which we know they don't get at home in the weekend.* He spoke of the lack of boundaries within home settings *so myself and the actual care staff in the day centres thought 'right it's time-out that they need on a Monday morning' It's just a few hours for them to be alone and not actually have somebody to speak to.* This he felt provided solitude for the person to relax after a period of over stimulation and he concluded *yeah I'm a true believer in that [time out].*

- In their relationships with people with learning disabilities, care staff experience emotions that affect their interactions

Julian felt that interactions with some people with learning disabilities can, on occasions, be stressful for staff. Recognising that lengthy interviews between staff and some people with learning disabilities can be stressful for both parties he made specific reference to his own feelings in such situations when he commented

*I think meetings tend to get quite tense kind of ..... you get the situation where you can find yourself kind of raising your voice, your tone, your mannerisms ..... recognise within myself that I need time out in these particular situations. I'll then say to them 'Look, I'll take a break. Go for a walk and we'll kind of re-adjourn in half an hour'.*

- Manipulation is used to ‘encourage’ people to do as staff wish.

When discussing management of behaviour that challenges services Julian recognized *denial of privileges* as one method such as *pocket money or the outing at the end of the week to the cinema* and he *always thought that that was a form of blackmail*.

*I have been witness to another member of staffing saying ‘Well you can go to your bed early tonight’ [mmhm And was that a child or an adult?] That was an adult with learning disability - the person was told to go to their bed early that night and that was the policy of that house that all householders had to have the same meal which I thought took away their choice because I certainly wouldn’t want to have the same meal as maybe 4 other people because everybody’s tastes are different.*

He did suggest however that the residential establishment couldn’t cook 5 different meals there needed to be a compromise. When asked if the person acquiesced with that decision that they would go to their bed early he replied,

*No - and it resulted in challenging behaviour and an incident happened and it’s actually making that staff aware – why did that challenging behaviour happen and take them right back to the whole day [mmhm] ..... ‘Look, when did that person’s behaviour start changing? Right after dinnertime after the argument you had about the food. What happened after the food? You told them to get their jammies back on and it continues on’ ..... and it was building and building and building until the end of the night when that person had obviously had enough, didn’t have the freedom of choice [mmhm] ..... and it ended up where that person had challenging behaviour with a member of staff and it ended in a physical kind of slap to somebody.*

This happened in the late 1990s when according to Julian *I witnessed that and myself being quite young and a new member of staff I can – I can kind of understand why people are quite scared to actually approach – ‘cause this was a member of staff that had been there for years. Although his initial response had been one of reluctance to speak out against a more experienced colleague he later reflected and felt I had to actually approach my manager and say ‘Look this is what I felt was done wrong’ and as a result of that things were put in place to change it so - I just didn’t want that client to go through that again.* The deference that new recruits pay to longer serving staff may mask bad practice if assumptions are made that length of service equates to good practice.

- It is not easy to speak out about negative practice.

Julian also spoke of the informal influence that an individual staff member can

have and this is not necessarily the more senior one. He said,

*I've been in teams where there are very strong characters and especially if somebody is new to care work and maybe worked in the oil – I've worked with a few guys who didn't like going offshore so they went into the care sector [mmhm] and they would look up to the strongest character who may have been there for 6 years and know the procedures off the top of their head, knew all the care plans, the medication but that's not necessarily to say that they're right. They've maybe just got the strongest voice and the strongest personality and I've seen people follow that [mmhm] you know – 'a bit like sheep'*

He highlighted the plight of care organizations in the *struggle to get the staff to stay in one place. Staff who have been there for years kind of 'rule the roost' a bit.* Again he highlighted the power of longer serving staff and whilst some will undoubtedly be very good clearly he was drawing on his experience when on a number of occasions throughout the interview he made mention of this.

- Some colleagues collude in the use of unacceptable strategies to meet their own agendas.

Manipulation of situations to suit staff rather than the people they are paid to support was a discussion point within interviews and several respondents in the study illustrated this with examples from their own experience. In that regard Julian was no exception. He stated,

*We had a service user that wanted to attend a strip club just because he wanted to see what it was like and it was a team of females and I was the only staff member there that was male and they all disagreed with this male client attending this club because they felt that they didn't want to walk into the strip club and they were thinking of their needs and not the client's ..... I said I could remember a female client in the house years ago who mentioned going to see the Chippendales because it was a laugh [mmhm] it was a humorous night and I believe a lot of the staff went along to support her so I just kind of turned the other side of it and said that's all this guy's wanting to do – he's just wanting to go into a place where females strip and OK see what it's like – end of the day it's his choice if he wants to do that .... ]*

This clearly had some impact on him as he felt staff over-ruled him. Although, as he stated, they were happy to support a female client in what Julian saw as a similar activity, this was not extended to the male client. He saw this as putting their personal feelings before their responsibility to support the client in what he wished to do. Instead, Julian accommodated the request by changing his shifts and he felt this was wrong.



## Case Study 4 - May

May commenced her career as an unqualified member of care staff within health. Following a period away from this position she decided that she would return to the position she had enjoyed. Since returning to this position she has undertaken further training. Providing some detail of her training she said,

*I have [done training] on vulnerability and I have I suppose on abuse as well because we did that in communication – what was it? – the values and attitudes and that kind of courses [mmhm].*

She also spoke of the benefit of experiential learning.

*You know the clients in the admission unit and the stories that went on in the community and what happened to them and how they ended up you know - being in hospital and stuff [mmhm] I would pick it up that way too.*

- A person may feel vulnerable but will only be 'at risk' where external factors come into play.

May was very clear about what constitutes vulnerability and that it differed from risk. She said *We could be at risk from anything. I could be at risk from walking out in front of a bus tomorrow – do you know what I mean? [Mmhm] whereas vulnerability is not understanding – not knowing and the difference is not being able to tell you something is right or wrong.* On the issue of risk she remarked *well I think it depends very much on the setting and where they are and there's different degrees of risk I suppose and then they can be in certain settings and not be at risk but risk can be anything.* Although she clearly stated vulnerability and risk were not *the same thing* but *linked*, at one point she said *the risk can be greater depending on your setting.* This is similar to the view expressed by April (Case Study 2) that risk is greater than vulnerability. She further illustrated this saying *they are easily led as in you would be able to be doing things without them actually understanding the consequences - without knowing it's wrong or it's right – that's what I see as vulnerability – they don't understand what's right and wrong and they just believe what people tell them to do [mmhm] That's vulnerability.*

- The vulnerability label can be conferred on another.

Although she was very clear regarding her understanding of vulnerability, it was apparent that if the conditions she felt created vulnerability were present then the vulnerable label could be bestowed. Yet she did not see the labels attributed to

care groups generally ascribed as vulnerable did describe everyone in the particular care group. She illustrated this in relation to older people.

*You can't put a label saying they are vulnerable just because they are old because some people are old and have it all 'up top' and they know exactly what they are doing but probably the majority of the client group are vulnerable.*

- Staff need to take measures to protect people from risks.

Often within institutional care people have become so reliant on staff making their decisions, or at least accepting of them so doing, that they follow their lead even when that means moving to a position of danger as May pointed out,

*Even the ones who are able to look where they are going don't look where they're going because they are so used to going out with staff and just going where the staff go [mmhm]. I know that's one of the first things I noticed when they came down – they wanted to walk to the shop and one of the members of staff was away to walk on front of a car and all the patients were following [laugh].*

And she had concerns regarding their transition from long term in-patient care to community living when they had led such a cosseted life.

*... you've also got the fact that they are a real danger to themselves [mmhm] so for them to come and go as they please is unrealistic because then you're going to be putting them in so much more harms way and things like crossing a road. All these guys have been in an institution for 30 odd years.*

- Labels are a feature of everyday life – people with learning disabilities also use labels for others.

Whilst discussing vulnerability May and I discussed people who are labelled to establish whether or not she felt care group labels have any association with the vulnerable label. She interpreted this question to be the labels that staff confer on them. Initially she referred to labels in relation to time within the service with those who had spent longer within the service being *clients or service users* because *it's nicer* than *patients* who are *coming in short term*. However she admitted she was using those terms as they are the term of the moment. On a few occasions throughout the interview May stated that staff do not do certain things as she said *it is not politically correct* and she referred to labelling in a similar way.

*Clients I think is a not too bad all round word [mmhm] I think it's quite a good one but service users – I think it's a bit detached don't you think? [mmhm] to me it's a bit like running a business [uhu?] you look after your clients – you take care of your clients and I'm not so keen on*

*service users – it's the favoured term at the minute but I'm not so keen on it – it sounds like prostitutes [laugh].*

Her reference to client and service user and the association she made with prostitutes was said in a tone that suggested that any association with prostitution would be undesirable.

- Changing labels will not change care.

May described a situation where staff use disparaging terms about people if not to them and she saw this as more acceptable. She described how staff use changeover reports to vent their feelings after fraught shifts when there has been violent and aggressive behaviour presented by patients.

*I have been in situations like report when people have been very high on whatever emotions [mmhm] and like a derogatory term has been used but it is never on front of the patients and it's never to the patients. It's more a venting of their anger based on what has occurred during the day [mmhm] You know what I mean? I've never actually seen somebody using a derogatory term to a patient as in calling them names or whatever.*

- Political correctness gets in the way of doing the right thing and describing situations as they really are

Speaking of the management of behaviours that challenge staff and in particular management techniques, May felt that as long as it was *very well monitored and – you know – kept in check to make sure that nobody was abusing it or whatever the use of seclusion is acceptable.* She qualified this with an explanation,

*I went to that talk with the autistic girl and she was saying that she hated people putting their hands on her – she'd much rather have mechanical restraint but she's not allowed to because that would not be seen as correct – it would be seen as wrong [mmhm] – I think from people that I worked with – we had it in [previous ward] when I worked there [mmhm] It was very well controlled and very well documented and it really did work for that particular patient [mmhm]. I think if a certain treatment works for certain patients then why, just because it's not politically correct we don't use it [mmhm] but if it works for that certain client and it improves them why not?*

This raises an important consideration in relation to person-centred planning if the individual when he/she feels able to make an informed decision is later over-ruled by professionals through fear on their part that their position might be legally weak if challenged.

She also associated political correctness with application of normalisation, or

rather social role valorisation theory particularly as it related to culturally valued analogues. She spoke of adults wishing to have toys and other things not associated with adulthood. But she felt that on reflection there has been a shift away from this since staff now feel they are infringing peoples' rights although which right in particular she did not specify.

*People go 'Oh it's not politically correct to do this now so we're not going to do it anymore' but then they realise 'No that's wrong' and they're infringing their human rights and views and what they get enjoyment out of or whatever. If you take all that away from them they're going to get bored and they're going to become bigger problems and you're going to have more problems in general [mmhm]*

Political correctness therefore is interpreted as a reason for some of the practices of care staff.

According to May people who have learning disabilities *don't understand what's right and wrong and they just believe what people tell them to do* hence they do not understand when they are being abused. This is similar to the view expressed by Marcus in Case Study 1 where lack of understanding is felt to be a defining feature of vulnerability. Even when people have been abused by those nearest to them they are accepting due to their lack of understanding subsequently conditions are ripe for those who would take advantage. May stated,

*It's a bit complicated with learning disability. That's the thing because there's two or three people here involved with that and have been abused by their families and things like that and then they see this great big punishment that we are not letting them go home and we're not letting them do this and we're not letting them do that but it's not that we're punishing them – we're trying to protect them and they don't understand that - they see them as that's their relatives and they love them and it's their family and it doesn't matter what they've done*

Whilst they may not feel abused by the family members even when behaviours deemed as abusive by others have taken place, due to lack of understanding they may feel more harmed by the actions intended as protective measures. Like Julian (Case Study 3) May felt that there was a need to redress situations that have happened in the family home. Julian described a situation where the circumstances in the family home impacted on the individual in a negative way such that 'time out' was necessary for that person's recovery on a regular weekly basis. Nevertheless this might be considered unintentional harm rather than overt abuse. In contrast May described abuse but she perceived the individual on the receiving

end felt more violated by the remedial action than the abusive situation.

- Abuse, particularly bullying and harassment, is seen as part of the lot of people with learning disabilities.

May recognised the damage caused by bullying and harassment yet she surmised *I don't think people generally think of that as abuse and therefore it's not abuse because it's not the PC* and therefore viewed less seriously than other types of abuse yet she acknowledged those as abuse of power. Her words indicate that if people do not think of actions as abusive then they are not. This would indicate that if the individual victim does not recognise abuse and the bully does not judge his actions abusive then there is little likelihood that behaviour will stop.

- Some types of abuse may be overlooked as they are viewed as less significant by support staff contrary to the views of the victims.

Though she expressed concern about all types of abuse she had particular concerns about psychological or emotional abuse in that *you can't see them and you can't fix them*. May expressed concern that one type of abuse is unlikely to happen in isolation of other types.

*..... if you're getting beaten that affects you but along with physical abuse you've got psychological abuse – they're not just going to be hitting you, they're going to be calling you names and saying things to you so psychological are the ones that are more damaging.*

Even though May spoke of the potential bad effects of physical and psychological abuse she felt that the psychological trauma of abuse might be more damaging yet she felt that it may well go undetected due to the absence of physical evidence.

- Policies are difficult to understand and time is not available.

Speaking of policy documents of which she was aware May expressed what she felt was the view of others regarding *jargon and big words* as problematic but she felt,

*..... it won't be possible to make them idiot proof but I think in the end that that is the aim you should go for is make them idiot proof because there is long words, big words and the way they are laid out it's a bit like - you go though one bit and then you'll have to go back to this other bit and then it becomes a bit more confusing when you're reading through them. Certainly that's what I found. It started on one bit and then changed to another bit [laugh].*

When asked if it could be better addressed in another way she felt,

*I know it would be an awful lot of time but I think it would be done better verbally - somebody who actually knew the document actually sitting there and saying this is what you do in this situation. ... you read it and it's very – you know.....?*

Like others in the study, May indicated that despite clarity of policy whilst reading the document she had in the past signed that she was conversant with it even though she realised she was not.

*As I say I've had 10 years of practice and procedures and yes when I started I know I didn't understand – I just signed the paper and I didn't fully understand what I was reading but over the years because you have read them so many times you do get used to them in the way they are worded.*

Since unqualified staff are often those who spend more time in direct care and support than do qualified staff this statement is indicative that it is essential that they are trained in a way that is meaningful for them.

- When normalisation is imposed on people we deny them the right to choose for themselves.

May's interpretation of normalisation was that all citizens should have the same rights and responsibilities and she returned to this in some detail several times throughout the interview indicating her strength of feeling on the issue particularly with emphasis on the responsibilities. The right to choose she felt was related to the responsibility to accept the consequences of the choice made. And she felt that no special case should be made for people who have learning disabilities not facing up to the results of their actions.

*Denial of privileges..... mmm ..... A lot of people say that that is wrong and that you should never be giving people consequences for their actions but I don't see that as wrong because I have a consequence for every action I do. If I'm driving my car and I get caught speeding I get a consequence. Do you see what I mean? I think the system lets us down an awful lot on that side of things because a lot of people say 'Oh they've got learning disabilities so we can't charge them. You know what I mean? They're being bad to that extent and you can't charge them because they've got a learning disability.*

Her use of the word *system* was in the context of normalisation theory and her thoughts of how her colleagues and wider society interpret it. In that regard she felt that people with learning disabilities were having a different experience from others which was abnormal. At another point in the interview May felt *if you don't*

*have consequences you'll never learn.* Her use of the term *bad* in the preceding extract and her reference to the need to learn in the next had paternalistic connotations although that may be less evident in the written words. She felt that people with learning disabilities know when they have done wrong and feel a need thereafter to be chastised.

*You know – even when I was – everybody when they are being brought up – everybody has always had a consequence for their actions whether they are doing right or wrong [mmhm] – you can't take that away from somebody just because they are in a care setting. They are still going to need consequences for their actions whether it be not getting a sticker, whether it be not going for a cup of tea – you know - and a lot of people need that for their guilt side of things.*

Her reference to the use of stickers relates to behavioural techniques with which she was familiar that might have been considered positive reinforcement whereas the *denial of going for a cup of tea* might be seen more as negative and punitive. She felt very strongly about this as is evident in her comment *If you use the PC term you're not allowed to punish – you're not allowed to punish bad behaviour and always reward good behaviour.* May saw this as a case of semantics *I mean if you want to call it punishment or consequences [mmhm] you know it's the same thing at the end of the day.* The following extract conveys May's frustration about the inability of staff to have an element of control in the management of situations that they find unacceptable.

*That's the way we are taught to see things which is all good and well but as I say people do need consequences – they need to know that they can't do whatever they want. Everybody needs that and I think.*

Her mood of powerlessness was evident in this regard and what she was conveying was what she saw as the abnormality of the manner in which she felt she was directed to deal with those challenges.

*Consequences are the same as a punishment [mmhm] you know or consequences can be everything – you know 'He's been good for three days so he gets out for, you know, whatever' [mmhm] Everybody's so busy worrying about their PC labelling and what's happening and rewarding good behaviour and not punishing bad behaviour – you can't have – everything's on a two way balance so you can't have good without bad, you can't have day without night [mmhm, mmhm] See what I mean? So you can reward good things all you like but you are still going to have to have a consequence for a bad thing.*

She was defensive of the individual adult's right to choose to have toys even though she acknowledges that in the past there have been strong assertions that in

the interest of normalisation people should cast aside childish things.

*I don't see nurses in the care setting that we are in that are derogatory about these things – you know that's what they need whereas I can see the other patients being derogatory to another patient because they are playing with a toy and they are 20 odd years old. But that's where we need to step in and say it's not wrong for them to play with toys but a lot of people will have had it drummed into their heads that they shouldn't be doing that cause they're adults.*

Though this case study addressed many issues, it was striking in the way in which two particularly strong messages permeated the entire interview that were less evident in others, those being political correctness and her frankness when expressing the need for people with learning disabilities to bear the consequences of their own actions.



## Case Study 5 - June

At the time of the interview June declared she had 16 years of experience within the care sector. Like April, she had broad experience within care and also as April had started out in a different branch of nursing before transferring to the learning disability branch. Another similarity between June and April was that she completed her nurse education outside Scotland but within the UK. Like Julian she had experience of both residential care and of care management. Her early experience of residential services was during a transitional period when people were moving out of the long stay institutions to homes in the community. She said *I really had a lot of knowledge about these people moving on and then I linked to the 4 units they moved to. June felt this served the people well because according to her I could say 'Don't worry, this is normal and it will pass' and just trying to reassure staff and clients that 'this is your new home and you know – it's OK for you to do this' because people didn't know how to live in a small environment and the staff didn't know how to work.* She elaborated on this point as follows:

*..... you know they were so used to this huge 25 bed unit with huge great catering kitchen and suddenly they're in this reasonably sized building but you know – it took them a long time to come to terms with it - you know they didn't have to get up with everyone else and have their breakfast by you know 8 o' clock in the morning ..... You know people [staff] found that really hard [laugh] [mmhm] 'What do we do now because we've been here since 8 and there's nothing to do because they are still in bed' [laugh].*

This experience clearly had considerable influence over her in the way she offered care and support thereafter.

- It is not clear if there is any difference between the terms vulnerable and 'at risk'.

*To sit and say what would I class as vulnerability – I think you'd have to be all day* was the initial response offered by June before she went into considerably more detail. Whilst much is written about risk management in situations where there is vulnerability June felt the reverse to be true where she said *I think some people are vulnerable and you can manage that so that it doesn't become a situation where they are at risk.* Her opinion was that risk and vulnerability are two points on a continuum.

*I see vulnerability at either end of the same scale that if somebody is vulnerable and you don't identify them and put things in place to maybe manage that then they will eventually become at risk for whatever reason.*

She then expressed the view *I think that is a really huge subject because I think everybody's interpretation of vulnerability is different and although the guidance is there, when you are out there working with people but she felt I think it depends on what experience you have as a practitioner about what you consider being vulnerable.* The inference here was that with increasing knowledge and experience comes an improved ability to assess vulnerability yet the two most experienced, April and June defined vulnerability. Whilst they were from very similar care backgrounds with many similar experiences there were also distinct differences. For example, April said *no I don't think it's the same thing [risk and vulnerability]* whereas June saw them as *either end of the same scale - I would say vulnerability and risk are on the same scale – they're just at either end.*

- There is a relationship between risk and vulnerability.

Although she identified them as *either end of the same scale* she suggested that by addressing one you could eliminate the other. This would seem contrary to the notion that they are both on the same scale.

*I think some people are vulnerable and you can manage that so that it doesn't become a situation where they are at risk [mmhm].*

Whilst April associated vulnerability with the intrinsic condition of powerlessness June associated it more with a condition resultant from external factors.

*.... actually vulnerability covers any part of someone's life and it might not be – I think everybody thinks 'Oh vulnerable' you know that could be sexual or physical or it could be financially and it's not just that – it's smaller things, just being vulnerable to maybe a dysfunctional family.*

- Vulnerability is easily spotted though not easily defined.

Despite the confusion that exists regarding the definitions of vulnerable and 'at risk' as indicated earlier June felt that people are able to spot it and that care staff can spot vulnerability with their own increasing experience. This would suggest that even where there may be lack of clarity in definition it is possible to sense vulnerability. She felt that vulnerability is associated with lacking social skills.

- Staff can protect people from risk but they cannot take away vulnerability.

June felt that the lack of social skills does expose people with learning disabilities to risk and she identified a situation in which social skills support work could

enable people to enjoy social situations but be alert to possible risky situations.

*maybe they could say something in a bar that might get them into a fight or get them being abused by somebody else because they haven't realised they have said something that's offended somebody or something that's inappropriate.*

In situations where there is a risk of financial abuse June felt that measures could be put in place *to reduce the vulnerability and to make sure that there is somebody keeping an eye and actually making sure that they have got money to buy food.*

- Policies are difficult to understand and time is not available.

June confessed that understanding legislation, policy and procedures is a constant challenge for care staff. Even in relation to her own position she light heartedly said *If I am honest myself, I can remember thinking 'Oh have I got to read all this? [laugh].* She expressed concern about the volumes of policy but she felt it was necessary that a way is found to integrate it into practice and she suggested *make it more live rather than a dusty thing on the shelf.* She went on to say that even educated people struggle with it and she wondered therefore how the information could be better imparted to those less intellectually able.

*Recently when I had a student – you know she had real problems trying to get her head round what social policy was, what legislation was and how they fit into practice [mmhm] because she was very confused about what is a policy and what is legislation and you know she's obviously an intelligent girl doing a degree course and she was struggling with it [mmhm] and how it works in practice so how are the people who are a lot of the care staff who are working there have maybe only left college – how do we help them get their head around it – maybe they're not as bright as somebody doing a 4 year degree*

To ensure that staff are conversant with policy June advocated *I think it would be better if it was more live - if people are really on the ball with it.* Of the policies she considered most important she said,

*If it's a really serious issue we do need to sit staff down in teams and say 'Look this is really important that you understand' and then taking it up maybe in individual supervision and saying 'This is why we sat everybody down. This is why it's important.'*

- There is a balance between duty of care and risk assessment.
- Staff need to take measures to protect people from risks.

June interpreted this as a way in which a balance could be made to ensure that people with learning disabilities can enjoy life experiences in the safest way

possible and she offered an example as illustration.

*A young person who likes to go out and mix and go to night clubs who might not have the social skills to know that in certain situations they could be very much at risk especially young girls so it's working with the vulnerability issues at the beginning to hope that we never get so far as them putting themselves at risk but in reality we all take risks and I think people with learning disabilities should be given the opportunity to do things that we would maybe consider as practitioners a bit risky [mmhm] I don't believe that someone in their twenties because they've got a learning disability shouldn't be able to go to a nightclub but ... and they would have a right to do that but it's about how we try and manage that with them if they are happy to let us [mmhm].*

She likened this to the way in which *any teenager learns these things through socialisation and their peers* but she cautioned *maybe people with learning disability have never had that so that's our job then to then do that.*

- A person may feel vulnerable but will only be 'at risk' where external factors come into play.

June expressed a view that even within professional disciplines individual practitioners may look out for and focus on different risks and that is based on their professional education.

*Obviously working in social work and coming from a health background you know I quite often go out and see people that are vulnerable maybe because of their physical health. Um I might pick up on that as being quite a big issue whereas another care manager might pick up on things within the home that they might see as putting somebody at risk or vulnerable to abuse for example if the family are not giving them access to their money or not allowing them to go out of the house or attend any type of service so they're very much isolated from the community.*

- When staff use labelling practices it is done to make sense of their world for example nurses see patients.

June had experience in different parts of the care sector so was able to illustrate the complexities of labelling practice within care. She spoke of the rationale behind the Local Authority use of the term service user when she stated *you might have other people who might be providing a service but they might be calling the person a patient, somebody from housing calling them a client and then I come along and call them a service user.* She explained that *a service user is anybody that uses a service – not only somebody with a learning disability so there is no distinction between whether it is somebody using an elderly service or an alcohol service.*

Like other participants in the study, June felt the need of some form of labelling inferring the absence of labelling sometimes results in people not being afforded the most appropriate service and supports. Referring to people with a diagnosis of Attention Deficit Hyperactivity Disorder she said,

*Um – I think health is much clearer in saying this is definitely someone that needs specialist support and the criteria's quite clear whereas in social work because we have a responsibility to everybody [mmhm] we tend to get lots and lots of referrals that are not very appropriate and um people are sometimes labelled inappropriately.*

But it is not only service staff who use labels. June also illustrated how some parents label their offspring in order to protect them albeit perhaps in a misguided way.

*a lot of parents – especially older parents will say um – will say things that surprise me sometimes 'they're too thick, they can't possibly get a job' [mmhm] 'They don't understand anything, and there's no point in speaking to them because their brain doesn't work properly – they don't understand anything so you speak to me' [mmhm].*

However she conveyed that they were not uncaring parents and the words were not meant to be horrible.

There are also the disparaging terms used *in some establishments ..... we've had terms like thicko, spasi, and that type of thing where staff have actually been removed from the service.*

It might be reasonable to assume that General Practitioners would be knowledgeable enough to judge when a person has a learning disability but June was not confident that this was so and it is clear from her statement that on occasions they do not know which label is appropriate.

*... and sometimes GPs don't know – I think they sometimes struggle with what a learning disability is and they might say they're mental, they've got mental health problems when actually they would have a learning disability [mmhm] so they're struggling with what's the difference between a mental health problem, a learning difficulty and a learning disability.*

Labels are also used to improve access to services however according to June *There is definitely a label attached to somebody and then they sort of go round the system.* Conversely though, the phrase people *go round the system* does not convey an impression of improved services. Rather it suggests a sense of

aimlessness.

Finally on the issue of labelling she explained Local Authority staff use the term learning disability to electronically record the care. Yet she conceded that this was at variance with the organisation's desire to provide inclusive services for all, avoiding labelling but in practice she felt that labelling could not be avoided. Thus different terminology is used for administrative purposes in private, defining people in a way that the organisation shy away from publicly with the more generic label service user. Hence although as a discipline social workers prefer not to label people, to make sense of the specialist nature of the learning disability service they find it necessary.

- People who have learning disabilities do not always realise they have been abused.

June spoke of lack of understanding several times throughout the interview and related it to vulnerability, risk and abuse. As an example of lack of understanding she said *a young girl going out in the community who maybe doesn't understand some of the social cues to be aware of and then she is putting herself at risk*. Later she spoke of those who might be deemed to have a mild learning disability but even they, according to her, are at risk.

*.... even if they are out in the community living in their own tenancy functioning fairly well with minimal support the vulnerability is always there that there is some aspect of their life that they don't really understand.*

She had some concern that *due to lack of cognitive skills– maybe some of the counselling and things that could be used are not going to work with these people so they are probably ..... going to be more damaged*.

- Power is a feature of abuse and it manifests itself in many different forms both in family settings and in paid care settings.

Of the family setting June said,

*I work with a lady at the moment who's mum is completely controlling her and completely controls her life um and she has limited ability to say 'I don't want this' She just goes along with it because she doesn't know what else is out there and I very much feel that her mum does bully her [mmhm] but mum would say 'No she doesn't know what she wants. I'm the best person to make decisions about her life'.*

However she went on to present a completely different perspective,

*Many people with learning disabilities will say 'I don't mind my mum taking all my money because she's my mum' even when that person is obviously neglecting them and not buying them clothes and not having adequate food in the house because they're spending it on alcohol let's say [mmhm] The service user will say 'She's my mum. You know? She has to have the money because this is her house'.*

This presents a challenge for staff whose first interest is the welfare of the person who has learning disability whilst also being mindful of the importance of the parent in his/her life.

- Personal experience influences the way that care staff view different types of abuse.

June felt that her *socialisation process is different* from that of people who have learning disabilities. Consequently she felt that they would not view abuse in the same way as she. She said *their values are different to mine*. This is similar to the view expressed by Marcus in relation to vulnerability and the things that might affect people with learning disability where he expressed the view that *They don't have the same values as people without learning disabilities*. June provided an example to illustrate this.

*I think when we looked into it originally it was abuse to start with [mmhm] and he – you know going back years and years back it was abuse to start with but it became – it became something that he got used to – maybe got used to is the wrong word – he began to get pleasure from it so he began then to seek it out and then you enter the situation – is he seeking it out because he wants a sexual feeling. Yeah I think it was abusive to start with because he wasn't consenting and then I think it became an experimental thing and so and then it developed into something he did all the time [mmhm] and sometimes he was very distressed.*

However June's account does not indicate that what was acknowledged as abuse was addressed or that the man was supported to make himself safe. As she pointed out he eventually sought out the sexual contact but it was not until there was physical evidence indicating trauma that staff wondered what to do.

*He would come back and be very, very distressed and um sometimes he would – I think when it became an issue was when he had returned with bruising [mmhm] and then as a group of staff we were like 'How do we deal with this cause he is choosing to stand by the toilets but when do we make the decision to step in and say this is going too far' [mmhm] because it isn't right – peoples' sexuality, people do all sorts of things [mmhm] in the normal population so when do we – where do our responsibilities lie as professionals?*

She questioned *When do we stop that happening - or maybe we don't stop it - we*

*just try and minimise the risk?* Clearly there was no will to address it at the point when it first was deemed abusive and the man was left exposed but when physical evidence was present this view changed despite the fact that by then he actively sought the encounter.

*.... but the problem was when he moved out of the hospital away from these contacts he – his behaviour really deteriorated and we were sure it was because he didn't have a sexual outlet [mmhm] but the staff were really concerned about working with him because he would go and hang around – he would go into a bar because he didn't know where to go he would go into bars and hang about groups of men [mmhm] um that were just there having a drink because he didn't know where else – what else to do [mmhm] and so how then does he find a sexual partner and so he was putting himself at risk.*

In this situation there is a paradox in that he was neither protected nor supported to protect himself; when he later exercised his choice in the matter staff at least speculated whether or not to intervene. Indeed there are some parallels between this situation described by June and the one described by April where patients in the hospital got into bed along with other patients and that was just seen by staff as part and parcel of the life of people with learning disabilities living in shared care settings, particularly health settings.

Reluctance to intervene in the absence of physical evidence is apparent in other types of abuse such as neglect, infringement of human rights, and emotional abuse which are discussed in more detail in the themes section of this chapter.

At several points in the interview June spoke of staff reluctance to intervene and in the following instance she spoke of the values judgement associated with it.

*When I was saying earlier you know about that man – that's what we are all struggling with because we all have different ideas about how to deal with it because of our own values [mmhm] so I don't think that people with learning disabilities would necessarily feel the same as me*

As is seen in her preceding quote the issue of a homosexual relationship was a question of the personal values of individual service users. Consequently, in the absence of clear policy this is what will guide staff. Like Julian, June felt that the longer the abuse continued the more damaging and yet she indicated in the issue regarding sexual abuse earlier that as time passed the man started to enjoy and even seek out the contact.

*When you are working with somebody who's been in long stay hospitals where they might've been sexually abused by another service*



*user for 20 or more years and then obviously that damages more – it is a higher degree of damage if you look at it in that way [mmhm] um but I think all of them are damaging and it doesn't matter if somebody is able to get over it, I think it's never going to go away.*

In this instance she had some concerns that what had started out as an abusive situation where staff had not intervened it eventually turned into an interaction the individual sought out as she illustrated.

- Some types of abuse may be overlooked as they are viewed as less significant by support staff contrary to the views of the victims.

Although she named *psychological* and *sexual physical abuse* she also highlighted *neglect, verbal* but she expressed concern that one type of abuse seldom happens in isolation of other types. For example she said,

*I suppose if somebody's being financially abused there is a good chance they are being neglected as well [mmhm] There's a good chance there's some other type of abuse going on [mmhm] so it's very difficult to say those are worse um but I suppose it's the ones that are more – maybe I'm just focussing on ones that are more well known and everybody would recognise as being abuse um especially if you go in and somebody's black and blue then obviously that's the main concern [mmhm] but they are all – I think they are all interlinked.*

Speaking of neglect and financial abuse she said *which comes first – the chicken or the egg scenario? Is it you know because the family are struggling financially that they've taken the money because of the lack of any kind of life impacts on the life of the person with learning disability so it's all tied in together so you end up – you really have to work with the whole family.*

- When normalisation is imposed on people we deny them the right to choose for themselves.

June and April had very similar views on issues relating to application of normalisation/social role valorisation. June said,

*... when I first started my nursing training there was this big move towards really strongly implementing normalisation or social role valorisation or whatever you want to call it and suddenly people who had rooms full of cuddly toys – suddenly the rooms were all bare and the cuddly toys were thrown away.*

According to June *it's caused a real struggle between allowing somebody to have their room full of cuddly toys if that what they want and treating them as an adult.* She laughed at this point saying *I've got cuddly toys on my bed.* She indicated that a balance must be struck that allows choice from a range of options that includes

possessions associated with adulthood. She went on to say,

*I think some people took normalisation to the extreme um especially in some of the wards that I worked in when I first started my training [mmhm] They were completely devoid of anything that could be seen as inappropriate in terms of age and suddenly somewhere that was quite homely with you know cuddly toys on beds and that sort of stuff and maybe nursery rhymes playing and things like that*

She then added pensively *normalisation although it did a lot of good, it identified that we needed to stop this block treatment of people and get away from those rigid routines in hospitals.* She also highlighted the negative effects which included *people's over reaction.* She illustrated the very negative effect with a really tragic story,

*I can remember – I worked with a man who used to carry a doll. He'd lived in a hospital for years and years and he had a very large old fashioned – I think it must've been his mother's – not china but hard plastic doll – she was big, she must've been about 2 foot and he carried it under his arm everywhere and everybody knew him by this doll and it was immaculately dressed and the doll was taken away from him because it was seen as being inappropriate but he wasn't even given the opportunity to have the doll when he was in his own home and it caused huge, huge problems in his behaviour and emotionally he did not cope with it at all.*

She said *I can remember being at meetings as a student with massive debates going on between qualified nurses ..... I could never understand why the measure had to be that drastic or why there couldn't have been some way of working around it but obviously as a student when you say that everyone says 'Oh well you're a student [laugh]'.*

Clearly therefore there had been considerable debate on the issue nevertheless despite the debate the man was still without his precious possession.

Arguably the values of a student nurse should have had at least the same sway as others but June's statement implies superiority amongst longer serving staff yet it is not unusual for student nurses to be whistle blowers regarding poor performance.

According to June *normalisation was this great thing and everybody was keen to be seen to be doing that and it wasn't just in health because I worked in local authority day centres as well and it was the same there you know.* To emphasise this point she explained,

*All the stuff they were doing in group work all of a sudden radically changed to try to be much more adult and I think that didn't last very long. I think people soon realised in the day centre that when you are trying to interact and engage with people you've got to have the right medium to do it and if that be a cuddly toy or a children's board game then you work from that but I think in residential people just went slightly over the top.*

Referring to the issue of choice June said *that's one area which I think since I've been in social work I can see a conflict between health and social work* and in this regard she drew on examples from her experience to distinguish between the different positions held by health and social care staff

*.... if they went into a unit and the staff said 'Oh he's only allowed to have one cup of tea because he drinks too much tea and it's not good for him' [mmhm] or 'He's not allowed 3 Mars bars because he is putting on weight' now most care managers would say 'You can't do that. If he wants to eat 5 Mars bars although you should be trying to work with him to try and make sure it's an appropriate intake, you can't stop him taking 5 Mars bars' whereas other people would say 'No he's only going to have – you can't let him have 5 Mars bars because it's not good for him and so we've made the decision that he's going to have one and if he wants to cut that in half or in 4 so that he has a little bit each day' and you can see this complete conflict going on.*

June felt that it is necessary to take a decision for an individual on occasions when the choices he/she might make could be harmful even if that means denying him/her the thing they would choose. She felt *sometimes you have to get a balance about whether it's an appropriate measure or not.* She suggested *if there's no other option and it [denial] seems to be effective and it's keeping someone – reducing the risk and keeping someone safe and keeping them well then I think we have to – we have to consider it as a technique.*

Drawing on her varied experience across different agencies June said *I think I can see that there needs to be a balance but sometimes care managers cannot see – don't see it in the same way as health staff and they [health staff] can't see what care managers say so there's this duelling ongoing, you know, and people say stupid things like 'Oh would you let them sit there and eat a whole pat of butter or what?' 'Well no I wouldn't but ...you've got to remember if he wants some butter he's got a right to have some butter' and you get into these silly arguments.* With this example of polarised views it would be unsurprising if a person with learning disability caught in the middle knows what he/she might expect or indeed may feel

the need to change depending on which type of worker is supporting them.

Denial was also considered in relation to denial of privileges. In mainstream society few adults would be required to modify their behaviour by being denied privileges by another adult. Yet this approach is still used in services although it has some supporters and some detractors. May did feel that the technique had some merit whilst April focussed more on the power associated with that practice and although she did not rule it out entirely she felt it should only happen after detailed discussion within the multi-disciplinary team with no one professional claiming all of the power. According to June,

*If it's only done because it's the easiest option to say to someone 'Right you did that so you're not going out today' then that's not appropriate but it's getting a balance between the two.*

Age appropriateness is a concept associated more with social role valorization rather than with normalization. People think of this in relation to language, clothing, possessions, etc and as was evidenced earlier in this interview and also in April's and May's interviews the 1980's – 90's saw wholesale destruction of peoples' possessions if they were not considered to be culturally valued for that age group. Marcus referred to the offence caused by referring to an adult as 'cute' whilst Julian spoke of the more liberal application of the theory in recent times from his experience. The more liberal approach was also preferred by June who said,

*I would try and encourage anyone working with a person with learning disability who may have a preference for maybe younger people's clothes or toys to be measured in how they deal with that – if they are using that as a way of engaging with you don't – you know, don't dismiss it out of hand [mmhm] and maybe if someone has got an idea that they want to walk around carrying a dolly when they are out in the middle of Aberdeen there are ways of working around that [mmhm] and you shouldn't just say 'Dolly goes in the bin' because it's not age appropriate [mmhm] It's not acceptable ....*

- People should not have a right to children just because they want them.

Article 12 of the Human Rights Acts states 'Men and women of marriageable age have the right to marry and to found a family, according to the national laws governing the exercise of this right'. Yet in this regard people with learning disabilities are not seen as equal citizens. As we have seen in case Study 1 Marcus felt that people with physical disabilities could be parents but not all people with learning disabilities would even though both categories might require family and

service support. He used the word *affliction* to describe learning disability where this was not the case when he described physical disability.

When posed the question whether or not people with learning disabilities should have children June said .....*yes but ..... mmm I say 'yes' and then I say 'but' ..... I think if somebody is making an informed decision to have sex and have a child that's one thing but maybe thinking that having a baby is going to meet some other end.* However despite her caution she commented *maybe they are completely unaware that they are pregnant and I think then we are into a completely different area but once somebody is pregnant whether they've got a learning disability or not I think they should be treated the same as anybody.* She also felt that when things don't work for people with learning disabilities who are not coping with parenthood no special case should be made for them and they should be subject to the same processes as others in this predicament.

*Like many other people in the population not deemed as being fit then they should be treated exactly the same. You know? The assessment should be made by appropriate workers as to whether that child is removed or not.*

Likewise she was not supportive of termination of pregnancy feeling that this should only be a consideration where *there are major health issues that need to be considered because in anybody else they would be able to have a child so [she] did not see why we should necessarily marginalise people with learning disabilities.*

She did not feel that *people with learning disability should be sterilised routinely.* She did however believe that *people with learning disabilities who want to have a sexual relationship should be able to do that and have access to appropriate resources and understand contraception and keeping themselves safe.* She also remarked *I think the problem is that the resources out there are not that good in terms of people working whether it be male or female about sexuality.*

June explained that she supports one woman who is considered to have developmental issues but her sisters are not diagnosed but she said *when you meet them they clearly have limited understanding and they clearly don't have the same skills as maybe someone of their age should ..... the parents are both learning disabled.*

Drawing on her earlier experience June offered the following as an example of the

challenges there are for the offspring of learning disabled parents.

*When I was working down south I worked with a family who had – the mum and dad had learning disabilities and they had a son and a daughter who didn't and mum – when I got involved the mum and the dad were in their sixties and seventies – mum was sixties and dad was in seventies and their son and daughter became their carers [mmhm].*

June went on to explain the offspring in this situation felt they had to 'grow up' more quickly than other children' but both were employed, had relationships and enjoyed life despite what might have been perceived as an impoverished upbringing. June therefore felt that decisions regarding parenting ability should be made on an individual basis.

## Themes

As detailed in Chapter 3 some emergent themes were best addressed across the entire sample rather than in case study. The themes were no more or less important than the case studies. Rather when the findings are considered in this way each complements the other. A similar approach to that used in the case studies has been adopted using italics to identify quotes of informants. As in the case studies themes are identified using bullet points.

- Vulnerability is exposed by lack of understanding and inability to communicate.

Defining vulnerability was problematic not only for those represented in the case studies but across all informants in this study. Some informants opened discussion with a general comment on vulnerability before going into greater detail. A common theme was *I think everybody's vulnerable in life*. A number defined it in terms of cognitive ability: *it's people who don't know what's right and what's wrong and they can be taken advantage of* others defined it in relation to the inability to speak out: *they don't feel they can come forward and discuss it or complain about it*, although there were also views that some were more able in this regard for example *some are more capable of voicing their own opinions and things than others are*.

Yet more defined vulnerability in terms of risk from external factors *it's definitely something inside them that makes them vulnerable to outside things* and a small number defined it as a combination of negative conditions of the individual *easily led - doesn't take much for them to follow somebody else* and compounded by external factors *some people would see weaknesses and pick on them*. Another said,

*..... folk were tormented and 'taken a len of', to use the local language, because they didn't have the skills to stop that kind of thing happening, so people that are weaker and don't have the same level of ability need some protection, and are always going to be vulnerable to abuse for folk that are determined to abuse them and are happy to use, or are determined to use that power that they have over people.*

One informant linked the concept to social functioning *because of limited understanding of what's going on around them, potential naivety and not being street wise*. Not being streetwise is one interpretation of an aspect of social

functioning and this was linked with increasing maturity by another informant when she said,

*..... maturity and understanding of concepts, their dependence on people and I suppose as they [children and other immature people] grow older then they become less vulnerable also things that make you less vulnerable are your sort of status and your ability to learn and you know look after yourself and obviously children don't have that.*

One started out saying that people with learning disabilities are not all vulnerable because some people are quite streetwise and that sort of thing and know a little bit more but finished saying at the same time they are very vulnerable.

In relation to external factors one commented *[They] are at risk of being ... not being abused maybe not being abused - maybe just being taken advantage of or whatever for different reasons.* Although abuse is addressed elsewhere in this chapter it would be remiss to avoid this reference to abuse where the informant does not view taking advantage of someone as abusive.

A small number acknowledged a rather elusive property. For example, one informant said *It's quite a hard thing to pinpoint isn't it?* whilst another said *That's a hard question ..... I would ken but I dinna ken how to tell you [chuckle].* Other informants, who struggled to define it, indicated that despite the lack of a clear definition, vulnerability can be spotted easily even by children who perhaps lack understanding of the concept but can recognise it and use it to their advantage.

*..... it's maybe young people that would target them I think. [Why do you think young people do that?] Because I think they're still growing up and they haven't really experienced life and they just dinna realise – kids hurt people whether they've got a disability. They possibly feel they have power over others who they see as less powerful than them.*

and one offered an example from his experience,

*I had worked in one particular place and the doorbell went ... and I went 'No it's OK I'll get it as I'm closer' and when I got , there was two young lads about 14 – 15 years old standing there and they looked at me and it was very obvious they were not expecting me to come to the door and they said 'can I get some sweeties' and I went 'No' but the other man gives us sweeties – you're not the man who's normally here – we want some sweeties' so I made it rather clear that there would be no more sweeties coming from that particular house. [mmhm] Now they had probably .... spotted that there was vulnerable people ..... [exhale] it's not devilmint – it's beyond devilmint - it's harassment [mmhm] because they know the people who are inside.*



Interestingly views were also expressed that people with learning disabilities can also spot this condition and use it for their own ends *sometimes some of the other residents can be manipulative to get sweets or juice from that person and you could see where the vulnerability would be.*

Some linked vulnerability to inability to protect oneself *they can't always avail themselves of the protection that is available for them.* One suggested that there are differing uses of the term vulnerable *if someone is vulnerable it means they canna help their selves or they are in a crisis at that precise time.*

Vulnerability was associated with communication difficulties – that is if they cannot communicate they are vulnerable.

*.... if they weren't able to, maybe speak up for themselves, to stand up for themselves, to tell people that they are not happy with - maybe what's happening to them or what's happening around them.*

The power of language created a distinction between staff and those they support in the view of one informant.

*I think somebody is vulnerable where there is a power imbalance. Where the member of staff is able to explain themselves verbally and the service user is not, so where there is an imbalance of power folk are always vulnerable to abuse, like somebody can use that power.*

Neediness in terms of reliance on services creates a culture where power imbalance can flourish as can be seen in the following expressed view:

*Well it's one of the things that we look at [in training] – what makes somebody vulnerable? - and people have lots of different ideas and a lot of it is around being dependent and if you have to depend on people or a service then there [mmhm] em because then you've got a – there may be a power imbalance.*

- Vulnerable on account of the label?

Although literature tends to refer to abuse associated with particular categories of people such as those abused within the domestic setting – domestic abuse or those defined within a particular care group such as child abuse or elder abuse only a small number of informants in this study felt that this had relevance. In relation to care groups being vulnerable one said *I ..... I would probably classify anyone with a learning disability as vulnerable* This was a view shared by another who said,

*I think that's quite a difficult one actually because I would think*

*everybody with a learning disability, within our service would be vulnerable. ... I mean the fact that they qualify for our service makes them vulnerable [mmhm] so I guess for us it's nae so much are they vulnerable but to what degree are they vulnerable.*

Of another care group one said,

*You can't put a label saying they are vulnerable just because they are old because some people are old and have it all up top and they know exactly what they are doing but probably the majority of the client group are vulnerable.*

Thus in this view if people do *have it all up top* then they are not vulnerable.

In general terms informants spoke in terms of care groups however when asked if vulnerability was associated with labels there were mixed views for example *I wouldn't say just because they're labelled learning disabled, I think each person would have an individual case.*

To the same question another provided a thoughtful response.

*Yes and no, 'cause some elderly people are really strong and stick up for other people and the same with learning disabilities – em a lot of people have got their peer group and they'll support each other and that's quite good and the same with children and young people.*

Yet again it is implicit from the comment that vulnerability can be spotted easily. This exposed position in which some people with learning disability live their lives provides opportunity for those who would choose to abuse them. The stage is then set for those who might act out their intentions and groom people and as is seen in the following remark they can be secure in the knowledge that the learning disabled person lacks the ability to convey their concerns and complain.

*Yeah I think so certainly with regard to learning disability. I think people could and probably have abused people with learning disabilities in the past because they know that they can't say anything or do anything or there's evidence or statement if they stand up in court or investigation [mmhm] and that would be a kind of manipulative type of abuse.*

Grooming was a consideration for another informant and she too linked this to the ease with which vulnerability is recognized.

*I feel that sometimes some people are more vulnerable to being abused than others because they can be weeded out because of - you ken? - because of their own vulnerability [mmhm] and if it's a carer that's going to be abusing somebody – it's like what they speak about with grooming [mmhm] and sometimes you can get that so I wouldn't say*

*it's just lumped to just one section or the other.*

Yet another interpreted vulnerable as the label rather than the care group and he saw vulnerability as something in the individual.

*It doesn't matter if they are labelled as vulnerable. It doesn't matter what anybody labels somebody as they are either in a position of vulnerability or they are not, I think.*

Having left the subject of vulnerability one respondent returned to it later and linked vulnerability to social status.

*Our culture is also if you don't contribute you are less valued or pitied and this comes from the industrial revolution. Our culture is such that we are reared to pity or feel sorry for the elderly, people who are disabled, etc. It's a cultural thing that disability associations are trying to change.*

- Staff feel the need of power/authority to manage difficult situations.

Power, control and authority are synonymous yet some informants viewed authority as more acceptable. Describing the need of staff to be able to manage difficult situations one informant said that behaviour management programmes *can work but I think they've got to be very well thought out with the entire team, em, very well documented and that everybody understands what is being put in place, so that .... not the power that you have, but the authority you have to carry out the incentive isn't used as a form of punishment rather than the incentive.* When asked to elaborate on how she felt that authority and power differed she said,

*I think it's quite easy for people to get these two mixed up. I mean we are in a very privileged position that - we care for these people tha - we provide for them and I think it would be very easy for that to go to somebody's head ..... Maybe authority wasn't the right word to use but .....we do have a position of authority because you know we tell them when to come and get their meals .... [mmhm] You say when they can have a cup of coffee [mmhm] .... We can, if we need to, restrict the things that they do within the ward so I think to that extent then we do have a certain amount of authority but I think it can quite easily turn into a power thing as well. I think we have to be very careful of the boundaries of that one because it would be quite easy to overstep.*

One felt that *everything's on a two way balance* in life and she referred to this in relation to rewarding good behaviour and punishing bad but she preferred to call the latter consequences rather than punishment.

Another said *I don't have a problem with appropriate discipline and control if the sole purpose is for the well-being of the client and not for the benefit of the ward.*

The lack of control that people with learning disabilities have in their own lives was illustrated in negative terms by a number of informants. For example:

*..... certainly some of the clients that we've had in the past get quite frustrated about the lack of control that they feel that they've got in their life, e, and the fact that they don't always get heard. At times they do feel they're sort of - not ignored, but their views and opinions are not heard and validated.*

One informant enjoyed when people with learning disabilities show their character when she said *you know some of the residents are really stubborn and they don't like being told what to do and how to do it. They can be quite stubborn and feisty and so on and some of them just don't like being told what to do* and when asked 'what happens with the one's that are feisty?' She replied *You just fight back [laugh] it's better when they are like that [laugh].*

In two different residential settings informants felt that those who were receiving support understood and appreciated staff's position of authority.

*Well some of them understand that I am the person that's in charge of this unit [mmhm] and we look after them [mmhm] I think – I ken for a fact that one [client] would understand that if we weren't here they wouldn't survive [laugh].*

Inasmuch as people with learning disabilities live their lives in very limited environments one informant referred to control within that context.

*Em ..... I suppose they accept the environment that they are in. [mmhm] and they accept the little world that they are in. But they'll always sort of show their individuality if they don't want to do something. They'll express it repeatedly even though it's exasperating for the people that they are working with.*

The inference was that choices over which people have any control are not major ones and this was also evident from comments relating to other services and the informant emphasized this saying *to a large extent they are very amenable to the environment that they are in and the regime that is imposed on them.* According to one *I dinna think they would understand discipline* and though he went on to say *I wouldn't just go in to my clients and say 'no' your no getting a cup of tea' I would give them a reason why,* he felt they would not be able to rationalize why but would be accepting.

Compliance was the term used by one who linked this to institutionalization. He said *It depends on the environment that people have been brought up in. Folk*

*comply - the institutional stuff - how people came to comply very, very quickly and labelling and institutionalisation and that kind of stuff is very, very effective at getting people to comply. This was illustrated as follows:*

*Folk can become frustrated and it can boil over in anger if they are being constantly controlled, and go along with that for a long, long time after the control has stopped. They will still look to staff for advice and 'what do you want to do', 'well, what do you think I want to do' – they will throw questions back at people and will look for staff to make decisions for them long after staff have changed their mode of practice so folk have been very used to it.*

A few informants spoke of the coercive behaviour of staff who do so in an effort to get people eat their meals. In most accounts this was seen as an attempt to ensure the people got nourishment.

*I think it's maybe easy for us to say 'If you don't come to the table you won't get your dinner' even if they don't mean it but I've said it myself. If you're trying desperately to get somebody to come to the table and think 'oh maybe if I say that then they will come' but that's not very respectful – we should be giving people their own choices ..... It is easy to try to use bribes.*

A number of informants viewed this behaviour as *blackmail*. Another informant illustrated this with an example from experience.

*One of our service users sometimes doesn't want to eat her tea and has in the past been persuaded to eat her tea by means of - em, holding up the thing that they actually want which is a drink, and saying 'you won't get this drink until you've eaten up your dinner'.*

Though according to those accounts this seemed well intended one spoke of a situation in a residential establishment she had encountered that certainly she did not view in this light.

*It's [denial of necessities or privileges] never happened [here] but it's happened [there] [and what's your thoughts about that then?] Quite angry and no I don't think it's acceptable and no I think it's pretty hard like [mmhm] I think it is hard – you know 'if you don't do that you don't get this sorta thing' – no I'm nae sorta happy wi' that but [Is there another way of dealing with the difficulty that's being encountered?] I widnae approach the care worker about it because really it's got nothing tae do wi' me – em that's all I want to say about it ..... [OK].*

In this situation the individual admits that she did not act to protect the person on the receiving end of the behaviour. The informant was a recently recruited employee with no previous care experience and she indicated elsewhere that she

found it difficult to deal with undesirable behaviours of colleagues.

Views on the denial of privileges were seen differently in different organisations and seemed to be influenced by the philosophical position of the organisation and interpretation of theories. One who had experience in different care organisations said *I think it's interesting when we talk about denial of privileges because that's one area which I think since I've been in social work I can see a conflict between health and social work.*

One informant who worked in a residential establishment in support of adults likened the management of problem behaviour to that of parenting.

*If they were young folk with learning disabilities as our own kids if they misbehaved we would say 'you canna have that because you misbehaved' [mmhm] 'and I think that was a wrong thing to do' [mmhm] because it's part of a learning process.*

Cultural influence was evident in another informant's comments when she indicated that sometimes people co-operate if there is some denial of privilege or behaviour management for example *'please come to the table now as I will not be able to keep your meal until tomorrow'* might bring about co-operation. And she said *sometimes a little punishment works.* However another said *generally I don't agree with the incentives and the treats ... treats being given as incentives but I can see that with some people it is the only way.* In those two examples it is evident that the 'carrot and stick' approaches are both viewed as having a place. Another working in the same organization viewed this differently providing an example that she felt was viewed positively by the person of whose care plan it formed a part. She explained,

*With our patients it works quite well – most days he gets – it works as an incentive though he doesn't get paid at the end of it but he gets to go out for the mail and he buys his paper and that [mmhm] but he – it's like if that things weren't there it would – I think he would find it quite difficult to keep himself occupied through the day [mmhm] and he can be so unpredictable but when he knows he's aiming for something then he is quite good at keeping to it [mmhm] and he needs to see it on a chart? We haven't got a chart for him but he is told like – if he threatens to hit a patient or a member of staff then he will be told that is your first warning for your mail round [mmhm] he gets two warnings and then the third time he is told that he has lost his mail round [mmhm] He kens exactly where he stands with it.*

Drawing on his early experiences in nursing one informant explained,

*The classic one in the hospital was that it was seen as being a reward rather than punishment that folks' fags would be taken away and would be handed back as rewards. I was trying to say that that was really a punishment because he had the fags to start with. If you want to give him rewards, give extra ones over and above his normal weekly allowance rather than taking away his cigarettes and handing them back and claiming that we were doing this as a reward.*

He was however fairly confident that that punitive type of behaviour management is not a feature of present day practice yet as is seen earlier one person indicated that drinks were withheld and other examples were offered by other informants relative to current practice. In a similar vein another said *Denial of privileges – you picked a big one for me 'cause it's something people just thought – again when I started my training that was something you did – it was recognised practice. That isn't respectful. There's no equality there. That is definitely saying 'We are telling you that this is what's going to happen and you will do this and if you don't we will do this'. There is nothing respectful about that.* One informant stated *to me if it is in their care plan em and it's up to the team the multi-disciplinary team to decide if that is to be done and I'll go along with that if it's been a decision for the right reasons things can be denied and I will follow that – if I disagree I will let that be known as well if I can but if it's nae listened to or acted on that's fine as well.* She clearly felt confident to express opposition within a multi-disciplinary forum however others lacked this confidence and this may be linked to knowledge and experience as well as confidence.

One linked denial of privileges or punishment with management of child behaviour. He then went on to draw parallels between his own situation and that of adults who have learning disability when he said,

*If I do something wrong I won't be denied any of my privileges [mmhm] you know – I can still go out in my car ... you know what I mean –unless it's criminal offence, you know what I mean? [mmhm] But I worked wi' a client who, you know, if they didn't put the dustbin out by 10 o'clock they were sent to their room and they didn't get to go to the club [mmhm] and you think 'Fit's that about like?' [mmhm] You know? That's just abuse [mmhm] You cannae dae that – sent to his room ... yes and he's thirty four years old.*

Another informant drew attention to the dilemma that faces those who balk against control. Implicit in this is the dilemma of compliance and rebellion. Consequently, the choice for some people might be to comply with what might be the more acceptable notion of authority rather than rebel and have control and

discipline imposed through a professionally constructed behaviour plan.

*For a lot of people amazingly accepting but that's how it is [mmhm] and for those who aren't they get labelled as challenging or difficult or em and a lot of the time you think 'I would do that if somebody spoke to me like that or expected me to go to bed at that time or whatever' I would do exactly the same. So some people do er fight against it but a lot of people really do fit the sort of ritual and routine and discipline that comes along with living in a service.*

Pragmatically this informant said *maybe they didn't like it but maybe it's just the norm for them and it gives them security and structure.*

An interesting final point in relation to discipline and control was made by one informant who felt that acceptance of this was a cultural issue. She said,

*I think it depends on the generation they have come from. Some of them – I think people who have been in contact with services all their life and they're now in their 40s and 50s are tending to be very accepting of the power relationships and if I look at that just in terms of the general population you know my mum was very – will pay attention to every single thing a GP tells her whereas if a GP says something to me that I don't understand I question it.*

- Staff have more power than the people they support.

Informants were asked how much power they believed people with learning disabilities have using a scale of 1 – 10 where 1 is equal to 'no power' and 10 equates to 'total power'.

Most informants felt that the balance of power was in favour of staff. Of those who felt that people with learning disabilities had more power than the staff one said *I don't know, maybe between 5 and 7* but she said *we do have the odd client that we've had in in the past that has been at the 1 end of the scale.*

Another remarked in an impassioned way *I would say - and it probably pains me to say it - but somewhere about 3 or 4. Folk certainly don't have the kind of power that I would like to see them having.* He explained this,

*We work with people with profound difficulties, sensory impairment, often people who have no verbal language at all and it can be very difficult to hear the other voices and sense a very still quiet voice, and it can be difficult to put in the effort to hear their voices, but I wouldn't say they are much further down the road than 4 out of 10. Which is not a pleasant thing to sit and look at, but I think it is realistic.*

Of those who were inclined toward people with learning disabilities being



relatively powerless compared with staff one gave a rating of 4 and clarified this saying that *they've got the choices and that but at the end of the day we've got to make a lot of – if they say 'I want to go on holiday' we say 'No you can't go on holiday just yet can you' so I think their choices are pretty limited.* Some felt that people with learning disabilities had next to no power at all. For example,

*I – staff need to do everything for them and they've all got non-verbal communication with the clients [here] who I look after. We've got one client who expresses herself quite well if you go into her space she'll tell you 'you're in my space – back off'.*

With a big sigh one said ..... *I dinna think they are completely powerless but I dinna think they have half the power so I suppose maybe 3.*

Another who was of this view stated,

*Uuuh .... well I think nil or one is not much power but I think if you can shout and demand and communicate - maybe in some aggressive way - then you are showing you have some power and you can shape how things are. It might not be with the best grace but you can shape how things are but on the other hand there's no point in em shouting out what you want if nobody's listening to what you are saying.*

After some thought she added *shouting against the system can result in sanctions and reprimands.* This is an interesting point since it would indicate that oppression is still evident within services despite the more enlightened theory being taught.

One informant spoke of the way in which people have little say over the way in which they are moved around in services.

*I would place them with only 4. Em because a lot of the time it's not their choice to be referred here [mmhm] It's kind of people have been thinking they are not coping so they have been referred to social work services or some sort of care service to help them [mmhm] so a lot of the time it's not their choice.*

According to Marcus [case study 1] people with learning disabilities are relatively powerless when compared with the power of staff suggesting that using a scale of 1 – 10 with 10 representing all the power with staff Marcus felt that for people with learning disabilities the score would be no higher than three. In relation to the power of people with learning disabilities he said:

*If they don't want to do something, then they can ensure that that happened to a large extent [mmhm?] or they'll fight.*

That people are unable to assert their choice just by saying 'no' to staff instead having to be more forceful makes them different from others. Thus by denying them the normative experience the staff who are there to support them to enjoy life actually create situations that lead to them being labelled aggressive or challenging.

At the other end of the scale one informant felt *They are living their lives much as they choose to in their own home and are quite empowered*. Suggesting that power is more with people with learning disabilities she went on to say *there are some who would be stronger personality but staff try to ensure that no one person dominates the others*. This is a curious interpretation of power since it would seem to be allowed only until staff decide to intervene.

A very different perspective was offered by one informant who said those most able to be assertive have all the power in a group living setting whilst those less assertive receive a poor service.

*Gosh ... some of our clients have no power whatsoever and other ones would maybe have as much as 5 or 6 'cause they do – they just click their fingers and say they are wanting out so that's it, it's done for them because they are more able and they are more able to voice concerns ..... and people will jump through hoops for them whereas there are other ones that are just left to do nothing - you know – they haven't been out for 3 days - they haven't been outside the door for 3 days but because they're not asking and they're not ..... they're just left to sit.*

She felt very strongly about this elaborating on her comments as follows:

*I know everybody has favourites and it's human nature blah, blah, blah but at the same time it shouldn't affect how you treat them [mmm] even if you have a favourite you treat them the same way – you can't – just because you like that certain person, you know, you can't jump through hoops and get everything organised for them in a day and because you don't like the other person it maybe takes 3 months for them to get out to get a pair of shoes [mmhm].*

Another remarked,

*I think they are quite powerful but then we've got another two that are not so powerful because they need everything done for them – we try but they still can't tell you what they want [mmhm] where the other ones can so they're more powerful than what we are [mmhm?] but we're still there for them.*

One felt that the ideal position should be *a joint approach between client and staff, if possible, with equal input from both parties*.

Only one informant referred to the role of advocacy workers working in support of people and as can be seen from his comment it seems to have made little difference.

*For the vast majority I although we have committees – we have groups who meet with advocates on a weekly basis and meet with managers on a weekly basis so I would say that they have .....[mmhm] they can put their points and their points will be listened to but when all's said and done the final decision is made by management.*

*Another felt it should be demanded that everybody has an advocate who would really kind of help and I think they may understand a lot mair. I think the difficulty just now is that there isn't enough advocates [laugh] so it's very difficult sometimes to get an advocate to come an' dae a particular piece of work.*

At the conclusion of each of the twenty interviews respondents were invited to add any final comments he/she wished to make that had not previously been covered. One commented,

*Some of those who would rate 5 on the power scale within the ward are very confident and would not see themselves as vulnerable.*

Even though she felt the balance of power was against people with learning disabilities within services, she felt they would not see themselves as vulnerable and this introduces a notion that even in a disenfranchised position an individual may still feel confident.

- In the absence of better strategies it is sometimes necessary to lock people into rooms to manage difficult situations.

Though the locking of doors is not viewed in a positive light by staff it is nevertheless felt necessary by many, perhaps even most. No informant saw the locking of a door to prevent egress as an infringement of the individual's rights. Rather they saw it as a duty they had to protect even if in so doing the locking of the door denies the liberty of those who do not seek or require that level protection.

The types of situations that merited locking of doors and denial of liberty was viewed differently across the informants of this study and ranged from duty of care (mainly due to patient/client safety issues) through to a strategy for the management of problem behaviour. The security of having legislation to support this was reported more by health staff (Mental Health Act) and local authority staff

(Adults with Incapacity Act) than by those in the independent sector.

Detention under the Mental Health Act was viewed as beneficial within health settings as it reduced the need for nursing staff to address issues of liberty for those in this situation. One unqualified health worker though felt that there was a paradox when people are legally detained but then allowed to go out from the hospital setting. He posited *I've always struggled with section patients being able to come and go as they please – I've always found that quite strange but people can still be on a section out in the community.....* When asked 'Can you elaborate on why you find it difficult with regard to people who are detained?' he replied,

*Well I find it difficult in that when they are on the ward setting if they decide to leave then you have the power to keep them there under the mental health act but if they get out for 2 hours on their own and don't come back I struggle with that.*

Interestingly one informant in a health setting said that although most patients were legally detained their freedom had been curtailed since the closure of the large institution where they previously resided on account that they had relocated into the city. She explained that in the large institution with its sweeping grounds people were able to go out in relative safety whereas now they have reduced work opportunities within a smaller service where the garden grounds are very limited. She illustrated this as follows:

*Some of our patients if they went out possibly down to the corner shop depending on how they viewed what people were saying or not saying to them or how they are looking or not looking how they perceived other people, they might then get anxious, get agitated which could lead to some incident or some out of the ordinary being said or .... [mmhm] which wouldn't have been the case where they were before because people round about them would have understood that and they would have felt safer as well.*

Another health worker spoke of the situation where one patient is not permitted to leave the ward and the consequence of that to all others when she stated *but normally we would have the doors open but it's just for this one patient at the minute.* However the locking of the door for one person is not unique to health settings. As was reported in Case Study 3 Julian described a situation where a day centre door was locked because one lady who suffered from epilepsy went outside and had a seizure on the public road.

One respondent spoke of freedom to come and go for those in her care as *unrealistic* since according to her *ones I worked with are dangerous to other*

*people [mmhm?] and you've also got the fact that they are a real danger to themselves [mmhm] so for them to come and go as they please is unrealistic because then you're going to be putting them in so much more harm's way.*

Freedom to come and go as one pleases was seen as a choice of the individual. Generally informants believed this should be so although notions of risk and duty of care were considerations. According to one *The media feed our fears of the big bad world and the probability becomes more real than it really is.* Bad publicity or the fear of it perhaps makes staff more cautious than is necessary and this was evident in some comments. However duty of care might be considered to be a positive responsibility of organizations but according to one informant *I've seen people deliberately use duty of care to curtail somebody's liberty or to draw them in or whatever so .....* She offered an example to show how strongly she felt about this.

*I think the worst thing that I saw with that – I heard, I didn't see it myself, was somebody saying 'Bus, bus, bus' and it was a sign that he was upset and it was 'Bus, bus, bus' and 'Mum, mum, mum, mum, mum' they had actually written in the notes as a plan that if he said this three times that he wouldn't be allowed to go to the [social centre] so effectively what these people were saying was these people weren't allowed to go out that night or that day so they had to stay in so their liberty was ... so they lost their liberty for daring to say they were upset [mmhm] They were saying 'I'm upset' and the nurses were saying 'We don't want to hear you telling us you're upset and if you tell us you're upset we are going to take your liberty away and we are going to punish you for it [mmhm]*

She concluded *So that was about one of the ... [laugh] I've got a few worst things here as I go through the tape but I suppose that was one of the worst things.*

One spoke of a recent development where one lady had *started stepping outside and ringing the doorbell, but when the senior was told about it - well the manager - actually she didn't find it that bad because she is only stepping out side as far as the doorbell and she's not, you know, going beyond the house much.* But he was concerned that *somebody could maybe just come along and take their hand and lead them off - some stranger.*

Relative freedom was offered to people living in a residential setting where they go from their own wing into the main part of the residential service however egress from the building was prevented by a locked door.

*Well that door there – most of the residents can get out just by pressing*

*a button which is fine because they are just going next door and it's safe because the next door's locked.*

Few claimed the locking of doors as a staffing benefit preferring instead to see it as duty of care and freedom was seen by one *dependent totally on how risky it is* although the risk assessment is generally done by staff. Of those who felt there might be some benefit for staff from the locking of doors one said *Obviously in some circumstances it does help staff because we can know who's coming and going but that is secondary.* Another made reference to other resource issues when she pragmatically suggested *I think that would be down to staffing because obviously you can't pay to have somebody on the door cause there would always be something needing done or .....such a lot of things come down to money* whilst another suggested *it's used as a means of managing the environment and managing people.* She added *I still think it's inappropriate but I have a greater understanding of why it's done.*

One informant commented candidly – *a lot of it is based on that particular patient ... [laugh] No I would say it's more staff related actually – I'm telling lies cause if there isn't enough staff they just don't get out and that's it at the end of the day [mmhm] and that's what I say – if there's not enough staff up the road they don't get to their classes.*

What was described as baffle locks – a mechanism that has a code number to allow access or egress requiring number recognition and manual dexterity to use – was felt to be an acceptable way of ensuring safety and the informant added *If there's not a lot of staff then aye I think it should be locked because it's for their own safety.*

Another working in the independent sector felt that hard pressed staff were compromised to an extent when he said,

*I feel myself that staffing levels are never what you want them to be because you go through a good patch when the folk you're looking after are really all being good and it's nice and peaceful wi' abody enjoying themselves*

He then pointed out that management in the interest of cost efficiency then reduce staffing levels thereby increasing vulnerability of those in their care.

Shortage of staff was also highlighted elsewhere in the independent sector as

reason for people being left unattended.

*I would definitely say it's based on shortage of staffing rather than – sometimes the care industry is quite short staffed [mmhm] and sometimes there isn't just enough staff there [mmhm] it can often be a major part of somebody being locked in their room and not being able to get much attention or ...*

One felt that if they are able to go out unescorted they should do so but he added *I think they should tell you where they are going - we only got one of my clients that could really go and he wouldn't get very far – he says he would but I know he wouldn't.*

With regard to freedom another said *I think that's OK if it's not a risk to them.* She identified the risks as *if they can't cross a road or can't do this or they can't pass a pub but they have to go into it.* She felt that it would be necessary to *take steps – not stop it altogether but just get somebody to go with them and try and go along that sort of lines rather than just say 'no you're not getting to do that' because the last time that happened this is what happened and that's what happened so we try going down a different route.*

Mostly, informants felt that the more profound the learning disability the greater the risk yet several observed that they should be able to have their freedom albeit accompanied *people I work with have quite severe learning disabilities and would have problems because they wouldn't understand the dangers of crossing the road and things like that they don't understand the danger and things like that so I think if they want out they should be let out but they definitely need someone there with them just to make sure that everything goes alright.* This protective measure provides a level of safety that people with mild learning disability may not have thus the corollary of this is that risk to them may in fact be greater.

On the issue of freedom one concluded *The word choice is very important .... but so is safety* and he went on to say *if there are safety needs that are more important than the need of choice then yeah – if doors have to be locked for safety reasons to keep people inside then yes they should be locked.*

Duty of Care and patient/client safety are inextricably linked and according to one informant this is a *Really, really difficult one because people are very tense about duty of care.* It was suggested,

*..... so it's really settling staff down about what is duty of care and why do we do risk assessment – we don't risk assess people out of their liberty [mmhm] I used to feel that risk assessment was a way to stop people doing things. It felt like that to me. The way that we look at things – the way I try to get people to look at things here is that risk assessment is a way of trying to get people to do things [mmhm] but it is scary.*

The 'scariness' comes from concern that risk assessment needs to protect organizations from possible litigation should things go wrong whilst trying to balance protection that enables. The two perspectives are often diametrically opposed. This was touched on by another informant who said,

*We have a responsibility to people themselves, to their families, to society, because that's what we are paid for - to protect folk and that may mean sometimes protecting them from themselves and stop them from doing things that will be harmful to them but you need to think why you're doing it.*

*Free as far as they can be* was the view of many and the balance was *I suppose you've got to weigh up your duty of care as well, against that.* The rationale for this was,

*If its something that's going to put that person at risk or in harms way, or is going to have an affect on their physical health, or their mental health, then I think we can have the right to step in there and discuss with the person and obviously explain to them why your maybe restricting their activities.*

This view was very strongly held by another informant who also offered an example by way of illustration.

*I think we need to work on the basis of the minimum intervention. But, the bottom line is that we also do have a duty of care and we have a responsibility to keep somebody safe.*

*We ask a question at interviews sometimes 'If somebody was going to cross the road and there was a car coming, what would you do?' And it's something people really, really stumble with ..... I'm pretty clear that you need to physically stop a person crossing the road if there is a car coming and they are putting themselves at risk.*

When asked whether interviewees might consider the question about allowing people to cross the road despite danger a trick question he responded:

*They really struggle with it and I've had somebody say 'Well at the end of the day if he really wants to cross the road I would just let him' ..... The person already worked with us and her practice in the past wouldn't suggest in any way that she would do that.*



The respondent indicated here that the interviewee may have tried to decide whether choice was more important than the person's safety in the selecting officer's mind and responded that way rather than provide what he believed to be her true response.

Most of the informants made reference to safety issues relating to people *that really don't have road sense. I mean we've got roads on all side of us here so you would be putting them at risk if you were allowing them to wander off and come and go.*

People with learning disabilities who depend on staff to take them out often have their freedom curtailed and reasons offered include *there aren't enough staff to cover .... limited staff and becoming creatures of habit, you know, going into work and just feeding and watering them .... enough staff on but there isn't somebody to drive the van ...*

Though some were unfamiliar with the terms seclusion and time out as approaches used for the management of problem situations many referred to it by another name. There were extremes of views particularly with regard to seclusion. For example one said *Oh no, no, no, no, no. That is definite we would never do that no, no – that days are gone.* And he went on to suggest that the only place for that approach is in a prison.

In the main the term seclusion was known to health workers or those who had previously worked in health. One who was opposed to seclusion on principle nevertheless acknowledged that in a small number of situations it had been beneficial.

*Yeah .... I think seclusion is a bit dated now but I think that's just a very personal thing [mmhm] but I've come across 2 or 3 clients in 10 years who can benefit from seclusion and er ..... I thought it was quite necessary but some of the times I wondered if seclusion was actually helping the patient or helping the ward. It gave us respite as well [mmhm] but .....if I saw seclusion recommended and used and I didn't think it was necessary I would state my opinion but the ones I've seen up until now as I say have merited it [mmhm] but er ... I'm sure there's other ways.*

*Last resort* was a term used by a number of respondents indicating that when all else fails there is little choice left to staff who are at the 'sharp end' of care often without acceptable strategies for dealing with the very real challenges.

*My opinion would be that I probably tend to that as a last resort, I would look down other avenues to see if there was anything else that could be done that was, sort of less severe than the seclusion.*

Another, who felt the need of structure if seclusion is ever used, remarked *I do have a few issues with seclusion if it's not monitored and there's not guidelines in place. I feel it should be an absolute last resort to seclude somebody* however she felt that in her experience if staffing levels had been adequate *time out would have worked just as well.*

Another who was not familiar with the term was almost outraged following a description as can be seen in her comments.

*Well I don't think that people should be locked in a room. I think that's madness because if somebody's wound up or upset and you go and stick them in a room and lock the door – even if you are looking in – it's just taking things too far – it's just like prison basically - I don't think that should happen and I don't think it's allowed to happen or it shouldn't be.*

One who sought clarity regarding the term seclusion went on to describe a situation of that nature she had experienced in a community setting, albeit not described as seclusion, when she said,

*Well actually I was working one place and that did happen to a person. I suppose it's a safe environment [mmhm] because they were locked in a room by themselves but they weren't – the door was shut but they couldn't open it and there was a window that they could be observed but it was really a locked door. It did work [mmhm and was that a one off or was it something ..?] I only worked there for a couple of days but it was definitely an ongoing thing [mmhm] and she did respond to it.*

For one of the informants inexperienced in care a response based on her own attitudes without the influence of an organizational position was possible. Following an explanation of both seclusion and time out she commented,

*I think those approaches should be used if people are going to be harmed or em ... I'm no' so sure about the seclusion and but if they're going to hurt themselves or hurt somebody else then - aye - as long as you go in and check on them and make sure they've calmed down and that sorta thing – then aye I think that's – I think that should be OK.*

Seclusion was an unfamiliar term for local authority staff however one informant from that organization felt it could have a place when he said *I think I would have to witness it firsthand ..... That person might need a room where there's nothing to throw, no tables and chairs and that does take their behaviour down ..... and*

*they might need some seclusion to calm them down.*

Following explanation, another described personal experience of seclusion and found it to be beneficial.

*Well, I guess I worked with a client who's really difficult em and when his anxiety levels are quite high he needs seclusion [mmhm] or time out em to be able to calm down otherwise others are at risk including staff and clients, you know [mmhm] and he would hit out whereas if he is secluded in his room or he has a – he has a grass area which he also has fenced off so when he is in there he is able to thrash it out and do what he wants to do – when he becomes quite acceptable in the group [mmhm] However I do think there are dangers in staff getting into that too quick, you know? [mmhm] so I'm nae quite sure how to monitor it in that it's quite a difficult one because he needs that – without that the whole place would collapse or him – he would collapse. He would end up in a much stricter setting [mmhm] so – a mair kind of hospital setting.*

On this latter point he did not elaborate however it is clear that he felt that if the use of seclusion does not work then hospital is a possible last option rather than seclusion where seclusion is still the last resort for other organizations. Even so seclusion is not viewed as an accepted contemporary approach for any organisation as is evident from the policies.

Reflecting on her time working within health one felt that seclusion was the only option as opposed to the last resort. Clearly in the context of that time she did not find it unacceptable however her views have clearly changed.

*I think in the days of the hospital that was like all that you had sorta thing and everybody and it was just ..... you just did it without sorta reading up and having more experience and you realise 'No I'm not going to do that – why could we not have done this' but then it was just what happened and you just followed everybody else [mmhm] but now having more experience or - we just don't do it now.*

Another also reflected back on her time in health but viewed seclusion differently in that she saw it as a protective measure rather than a punitive one and this clearly made it more acceptable even though she did not claim it to be the best approach.

*Certainly in my earlier years in the hospital I had .... with the resources no better way of supporting the person at that time while protecting the rights and safety of others [mmhm]. You had somebody who was hurting other vulnerable service users so you can't always walk away and go 'Alright staff just back off and keep out of their way' the first person they might go for is somebody very vulnerable ..... so it's that whole compromise of living with a lot of people and balancing one*

*person's rights against another so I have seen it have it's uses.*

Even though it is not viewed as a positive approach in contemporary care it has nevertheless been found beneficial in some care settings.

*.....I think with the one person I'm thinking of it was [mmhm] but they also needed sedating as well [mmhm] and – so sometimes it was just a case of em seclusion room first and then get the medication ready. Occasionally being put in that room just calmed him down completely because he was away from everybody and once he was in that room he was quiet and it was like he was in his own little space and nobody was in there so he was quite calm once he was in there.*

It was also viewed as *fine if warranted and agreed that that is of benefit to the person but it shouldn't – it never is done light heartedly.* This is supported in Case Study 4 where May detailed a conference presentation by a lady who has autism and who explained that she much preferred seclusion rather than people touching her whilst restraining her during periods of distress. According to May this lady preferred seclusion even though it is outdated as a preferred approach.

Time out was interpreted in two very different ways; firstly where the individual chooses to have private time away from others - *chill time* as one person put it and secondly where staff feel the need for an individual to have time in private away from reinforcements. One said.... *I think sometimes they need timeout but it needs to be their decision. I mean you can't go and say 'Right you go in there' you don't do that. You don't do that at all!* However she did feel that sometimes it is necessary for staff to decide on this and she related this to occasions when people are sexually stimulating themselves in the shared living space of residential establishments but don't necessarily choose to do so in private.

*..... if they are obviously doing something they shouldna' be doing – you know 'Go to your room and do it there' and then we just go along and that's different and everyone's looking at them and they don't want to see someone doing that so we do do that but other than that.*

This was also a challenge faced by another respondent who said,

*I've experienced somebody who is being particularly vocal in the dining area and being asked if he wants to go to his room and being taken to his room and he is still being vocal and just being left to calm down, but not actually somebody being violent. [mmhm, and when he's invited to go to his room does he go willingly?] No, usually not willingly because he's so agitated that he's not willing to do anything you ask him. Often it's because he is trying to masturbate and people are saying, 'Don't do that here', because it's in the dining area and it*

*seems the best thing for him is to go to his room.*

Another felt *it works when they are by themselves when the door is open and they have their relaxing music or whatever on.* In a residential setting though even this approach can be problematic since as one informant claimed the personal space within the accommodation does not necessarily lend itself to this.

*Time out – I think it depends on the resident – on their level of understanding and if the resident understands that they are going away to their own room for 10 – 15 minutes – I’m not speaking about hours on end – 10 – 15 minutes just to think about something that they have done but then you have to be careful not to punish for too many things [mmhm] I think time out is maybe a safe enough option to dealing – for a short period of time – 15 minutes but ..... not walking away.*

According to one informant *some people enjoy it [time out]* and he went on to provide an example from his experience.

*I know a woman in the past who uses lots of objects to indicate what her wants are to the staff and that has been extremely successful and a lot of her challenging behaviour has reduced quite a bit. When she wants a bit of time to herself she gives an empty fag packet to the member of staff and uses it as one of her signifiers because she was aware that sometimes a member of staff disappeared to have a fag. [Oh right] so she was able, rather than becoming upset and hitting folk, she is able because folk have spent a lot of time working on her communication, over the years, to say to them, here you go I want a bit of space. Give me 15 minutes or whatever and that is much more positive than asking for it.*

Asking someone to go to his/her room was not viewed as time out by one informant who said,

*Time out is something I’ve never really used. One lady in particular that I can think of that she does get a bit agitated or angry and they just ask her to go through to her room and in 10 minutes we will go along to her and chat with her about what is worrying her.*

- Offensive labels are sometimes used by the public but sometimes also by staff.

Disparaging terms that are used to describe behaviours of people with learning disabilities are commonplace in Grampian for example window lickers, and watch breakers amongst others whilst terms describing cognitive ability are also widespread for example *spasis, retards, um spastics and stuff like that.* Though the latter is not actually related to cognitive ability many young people make this connection. One informant even highlighted examples within services where staff should have known better. She said *people are spoken to in a patronising way and*

*they are labelled by their negative aspects such as 'biter' and we recently dismissed someone for calling someone who masturbated 'the wanker boy'. People with learning disability often carry a history of which they cannot rid themselves and this was evident in one remark when one said *even some of the terms patients will come out with themselves – things they have been called in the past.**

Another example was provided by one informant who drew comparisons between the experience of a person with learning disability and himself. Of the person he said,

*I had a client that I worked wi' who at 16 hit somebody in a college environment –hit somebody over the head with a – a piece of wood [mmhm] and now this person is still regarded as violent and dangerous but that's the only incident that I can find [mmhm and how long ago did that happen?] Well when I was working there she was 28.*

Of his own situation he shared,

*I mean [exhale] when I was sixteen there was things that I did then that I wouldn't dream of doing now ..... [mmhm] and you know – I had fights when I was young but they're nae recorded naewye and naebody's put a label to them and naebody's saying, you know,' you're aggressive'.*

Another example from practice related to occasions when there has been a particularly challenging situation in which there has been violence after which she has heard a colleague refer to the person as a *shitpot* and she went on to say *I just canna see how you can relate to anybody in that way at all.*

Within care services though staff tend to use the preferred terms of their respective organizations. This latter point was evident in Case Study 5 – June, where she highlighted the complexity as well as the pettiness of this posturing. Another, working in the independent sector also spoke of changes of terminology when he remarked *within our services we used to refer to people, when I first started with [name of organization] as clients then they changed that very shortly after I started to service users so we refer to people as service users.* He went on to say *I'm pretty keen on referring to people as people. I think in documents I prefer not to use a title and talk about a young woman or a young man, rather than a service user.* However within services this is sometimes just a sanitized version of labelling since it is sometimes used to describe a person who is not so young as to warrant that description and may even be viewed as a way of referring to adults in

a way that conveys immaturity. It should be noted though that this informant did not convey that impression.

One informant who worked in a health setting explained that within formal settings one label is used but in other less formal situations different terms are used.

*Em – first of all you would have the kind of professional label the doctor's proper diagnosis and things like that and then there would be the ones we use amongst ourselves probably that are less ..... not less professional but you know? - in lay man's terms [mmhm] when we speak amongst ourselves if we are describing anybody or referring to anybody [What sort of layman's terms would you use?] Em ... that is hard ...em ....I suppose it would be .... I'd say – oh no that's a hard one .... More light hearted – it's more light hearted with a touch of humour added to it [uhu] so it wouldn't be derogatory.*

One who referred to terms of the past as *mental handicap* or *challenging behaviour* felt the more contemporary label *learning disability covers everything now*. According to her,

*I've probably heard quite a few and not all of them are particularly correct in any way - quite derogatory ones I've heard in the past.*

She explained that this was behaviour of children in school and this was similar to responses for others and she found it *quite distressing sometimes because these people, you know, don't ask to be born that way or to have this life*. Interestingly one informant explained that people with learning disabilities whom she supports also use labels for others in order to make sense of their world. She works in a nursing home where there is a 'learning disability wing' within a nursing home. She said *Well our residents here call the people through there the old folkies [chuckle] so that's probably the biggest difference but even though we are separate through here it doesn't feel like we are separate most of the time so it's mostly just – I've never heard anyone being described as different. Sometimes people say 'Oh the dementia patients next door*. Although one informant claimed he disliked labels he subsequently referred to the people he supported as *people with LD* on numerous occasions throughout the interview. However it was not clear if in stating his aversion to labels he meant offensive labels and did not see the term he used in the same light.

It is not only children who use disparaging terms as according to one informant *Some time ago I overheard staff outwith work on nights out describe people inappropriately with labels*. On this issue she concluded *you can change practice*

*but it is more difficult to change attitude.* Another informant spoke of the manner in which some parents refer to their offspring. He said,

*They'll say 'You see because he is stupid he doesn't realise' you know or 'because he's an idiot ....' and you think 'Oh me' [exhale] [mmhm] This is nae right you know.*

One who felt sensitive about how labels might be perceived by labelled people and in particular those with learning disability said,

*My own personal feelings is that if I go up to somebody and say they've got a learning disability it's a label and I think labelling is quite a stigma to somebody especially when they – when the clients can't express 'I don't like being called somebody with a learning disability' [mmhm] but I think learning disability is better than some of the labels that they had in the past.*

In relation to the manner in which people in general relate to those with learning disability one said *if you are walking out with them you would probably get people shouting at you as well* but she later clarified *you find it's more young kids as well that shout at you and it's always in a group and they never do it by themselves - some of the things that they shout it's not very nice.* When asked to elaborate on this she said *Like ....[exhale] I don't even like to use the word like ' Oh where do you think yous have come from' or 'what are you doing here' and calling them like 'feelies' you know things like that and it's just horrible.*

- People with learning disabilities are not viewed as equal citizens.

There are many ways in which people with learning disabilities are viewed that is different from other citizens. Denying them their liberty without just cause is one example. In addition to protection for safety reasons people are protected because they are viewed as childlike or childish and as some informants claimed, they viewed them as they viewed their own children. This allows staff to rationalize a paternalistic approach to care that is risk averse for the organization whilst limiting the individual's life experience. Commenting on the childish quality one informant said *I suppose some of their behaviours could be described as being childlike or childish, but I would say everybody has got a childlike quality to them* whilst another said *that's got a lot to do with how dependent somebody is so the more dependent they [people with learning disabilities] are the more likely they [staff] are to view them as children.* This was not a unique response as others confessed to having possessions normally associated with childhood. One informant offered as an aside *If someone's had something for a long time and likes*



*it who are we to take it away or to say you're too old for that and take it away – especially if they've had it for a long time. Yeah I've got things I wouldn't part with, you know?.....[chuckle]. Another questioned What harm is it doing them and a lot of people collect cuddly toys?*

A number of informants felt that generally people are *patronizing* to those with learning disabilities and a couple even admitted that they recognize patronizing behaviour in themselves when they reflect though it was conveyed that it is inadvertently done and without malice. An example of patronizing behaviour was offered by one who said,

*I can remember an incident and it was a female patient who was quite small for her age and it was assumed – we were actually going into a pub for a pub meal to watch a sports thing on the TV in the pub and the bouncer said 'I'm sorry we don't let anybody under 16 in' [laugh] I said 'But she's not under 16' Then he realised that that 'Oh right enough – that is the case' but then he made it just as bad by saying 'Oh well [and spoke totally above her and said] well if you're happy enough there's seats round at the front and you can get easily round to the bar and ..... and the woman was more than capable of knowing exactly what he was saying and how he was saying and she did take offence to it.*

Another compared the experience of parents of learning disability with his own parental role and he was clear that there is a difference. He felt *parents often see themselves as having that parental role for a lifetime, you know,*

*You will often hear people often calling them ... kids or children [mmhm] and I think that's often the other difficulty for parents you know? whereas with your own kids they grow up and they eventually do kind of start arguing back [mmhm] and they think about what they're doing and why they're doing them and ... you ken? and you get that sense of 'Oh they're growing up and they're goin' awa' from me' [mmhm] and perhaps people wi' learning disabilities never get to that stage so that the person is always of the assumption that they have some sort of control over choice for that person.*

Mental age rather than chronological age greatly influences the interactions between staff and the people they support. As one informant indicated,

*.... I think in some cases they can be seen as being treated as childlike [mmhm] sometimes I think they go by the mental age rather than the actual age [mmhm] which can lead to problems [Can you elaborate on that?] Well sometimes with behaviours you will hear people saying they are acting like children - like a spoilt child.*

The engagement with people through the use of activities also reflects this view.

*... the games reflects the mental age – some activities you might do with children but that is subconscious [mmhm] and you just do the things sorta that they are capable of doing rather than ... but I suppose to an outsider you could be seen as doing some childlike things with them.*

Engagement using different media should never be overlooked on account that it provides a communication mechanism where perhaps no other approach is successful. As one informant explained,

*... one of our residents that likes playing with rattles [mmhm] but because she likes doing that we take that into account but we address the issue as adults and they are addressed as adults and they do adult things and mix with adults [mmhm I was actually going to come onto that at a later stage in the questionnaire but, perhaps since you have raised it, could you tell me a little bit about the rattles and what your thoughts are about that?] Yeah my own personal view is because she likes – the client likes playing with rattles em yes because it's her communicating her views and stuff and if she's in a bad humour the rattle pitch is higher [mmhm] if she's in a bad humour [mmhm] and if she's in a happy humour she just sits and rattles [mmhm] and I'm fair enough wi' it – I'm all for it.*

Another spoke of the importance of communication but she explained how some staff struggle to find an acceptable method and resort instead to childish talk.

*... sometimes when you go into provider organisations some staff that might be struggling with developing a relationship you find .... talk in baby talk because there is a lack of understanding about how to communicate with somebody in a way that is respectful and age appropriate.*

The manner in which people talk to and about people with learning disabilities ran right through all interviews and it is clear that, whatever their philosophical positions, their behaviours belie this.

*Sometimes people will say such and such was acting like a child today and [mmhm] and that's something a child would do and that is something that does happen [mmhm. Have you a particular view on that?] I think it is wrong because they are all aged over fifty and above but they all speak about what's appropriate for people's ages. I do hear some people saying things and I do cringe.*

This informant however rationalized this by saying *but I am quite new and a lot of people have been here for a long time.* This deference to seniority assumes that years of experience necessarily means sound knowledge. Tantrums are behaviours normally associated with a developmental stage of childhood and one informant working within the independent sector referred to this behaviour.

*We treat them – if it's someone taking a tantrum because they hadna*

*gotten their own way - we'll ask them to go to their own room and chill out [mmhm] and just think about what they have done and there is a couple here that just will go away [mmhm?] and think about it and once they've had time to think about it they will come back and say 'I'm sorry' [mmhm] or else you've just got to accept what they can do.*

The preceding statement not only refers to tantrums but to failure to *get their own way*. In adulthood most people use negotiation skills to achieve their aims and desires however the balance of power implicit in the statement seems to be stacked against the person with learning disability.

Age-appropriateness as a concept was discussed by one informant when he related it to theory whilst describing its application in practice.

*We've tried to move away from that. We've spent a lot of time with looking at some of the normalisation stuff and the training that was done for everybody at that time, talking about age appropriateness and looking at how things were age appropriate. There still is, or can be, references to people in childlike ways, and some of the banter that people will have can be quite childlike, sometimes some of the people who you are working with, will enjoy having nursery rhymes sung to them and that sort of thing, so there are some child-like things that are attractive to some of the people we are working with and have continued and have persisted.*

He concluded this comment by saying *I think an absolute obsession with age-appropriateness was possibly taken a wee bit too far*. One felt that people with learning disabilities have childlike minds but she said they are treated as adults however she explained that they had to make their choices from those associated with adulthood unlike other adults whose choice is not so limited.

*They're not viewed as a child. They are viewed as adults but with having a childlike mind as in they don't make the same distinctions between choices as an adult of their age – you know – if they don't do this they won't get that. You know I hear a lot of people referring to them as having the mind of a child but they are not viewed as children that's the thing but things have gone too much the other way as well because like some of these adults like playing with toys [mmhm] but then we're told they're not allowed to because it's not age appropriate but that's what they get their stimulation from – that's where they get their fun from so why can't they?*

In some contexts therefore people with learning disabilities are expected to cast aside associations with childhood whilst in others they are denied the same rights as other adults. For example they are prevented from marrying and founding a family. One informant used an example from practice to explain how one couple

had been prevented from marrying.

*Oh that's really awkward because I haven't – it's just recently that I've come up against it because a couple who attend here got married [Oh I saw that in the paper] Well they canna get married because they dinna understand the vows they're taking so they can't get married so they got blessed ..... [Do you think all people in wider society fully understand the vows they are taking] [laugh] No so we shouldn't be getting married either [So who suggested a blessing?] I don't know 'cause it wasn't here – it was their home. They had been together for 5 years or so ..... [Clearly then they understand the importance of a close relationship?] Mmhm. There was another couple who come here got married and they're OK [And they live together and did you say they are married? But the other couple weren't able to be married because they didn't understand and yet they have been together for around 5 years?] Mmhm 5 years.*

Whilst marriage was not discussed at great length by respondents, views regarding having sexual relationships were more polarized and having children even more so. On the issue of having a sexual relationship one said ..... *I may be old fashioned but I'd have to say no. I keep saying about each case but the social consequences of a sexual relationship and a pregnancy and is the person able to look after a child and the complications for the child but certainly I don't think everyone has a right to it I think it would need to be .....[voice tailed off].*

Another acknowledged *I do think they have sexual needs as well like the rest of us so I think it is a really difficult thing to think about because people think 'Oh they have learning disabilities and it isn't appropriate ....' But I do think they obviously have needs that need to be met as well but it depends on the individual and their views and their thinking.* Another had not considered the possibility of people with learning disabilities being sexual beings. The assumption here is that they are in some way asexual however after this notion was introduced he said,

*.....that's a hard one ..... Em ..... Yes I think they do but then really I haven't thought about it. I don't know how they could go about it in the best way or ... but I think they do have a right to it [mhmm?] if both are consenting then they do definitely have a right.*

Some felt that, like everyone else, people with learning disabilities should be able to have a sexual relationship. Fewer however felt they should be permitted to have children. One who was of this view commented:

*Personally I don't. ....If some of the residents here had children they would probably have been taken into care straight away or ..... I don't think they should just for the sheer fact that .... You know .... How do you explain to someone with a severe learning disability about what's*

*happening to their body when they are pregnant – all the changes that they have when they are giving birth or having to go to hospital to have the operation then how do you explain that the child they've just had has gone away and I think that could cause more upset than it would be worth just to be correct- you know?*

Almost all of the informants considered contraception as a responsibility of the women and one reason for this which was offered was in response to a prompt.

*[OK so when we are talking about contraception we are talking about women?] mmhm .... Men as well but having to explain to them and show them - it wouldn't be easy is it?*

Of those who agreed that contraception should be available most felt that it should only be given with informed consent.

*Yes I think if they have an understanding as to why the medication has been given but I don't think I'd feel too comfortable about giving someone the contraceptive just as a precaution that sexual relationships might be happening some time in the future.*

Of those who felt that contraception might be appropriate and perhaps even given where the individual is not able to give informed consent only one suggested that where the latter is the case a long acting depo contraceptive might be considered.

*Possibly – if you know she is going to be sexually active without the knowledge or the understanding of consequences then Yes you could be thinking about depo provera the injection as a safer method [inaudible] [uhu and that would be with or without consent?] Preferably with consent but of course if she doesn't understand [inaudible] wouldn't be proper consent so in that case if the families involved, if she's still got her mam, you would be involving other people if possible [Even if she's an adult?] Even if she's an adult – again I would still be doing it. And again if any of mine got into a situation like that, that's what I would want [uhu, uhu] whether you would go along with the mum .....*

As can be seen she was responding based on her own values as a mother and what she would wish as a parent.

Whilst informants were able to contemplate contraception fewer felt they could support termination. Even so some were able to express a view on the appropriateness of such a decision.

*I do think if someone's got severe learning disability it [termination] should be considered if the person couldn't go through a pregnancy – you know if they were in danger it should be considered but it's very difficult to even think about isn't it [mmhm yeah it is].*

One who had personally experienced abuse felt,

*Oh that's hard ...I think if they've got a disability and they canna really think for themselves I think you should consider termination especially if it's abuse .....*

Curiously when considering whether or not people with learning disabilities should have children one saw the degree of disability as a deciding factor yet he felt differently in relation to people with very serious physical disabilities therefore learning disability for him was a greater 'affliction' than physical disability as can be seen in his comment.

*If their learning disability was so severe that they had no understanding about pregnancy, childbirth and being a parent. [Mmhm, so that more than the condition that the person has?] Yes, because you could get somebody with a fully functioning mind who is virtually immobile, and it would still be considered right that they could have children.*

In this example cognitive ability outweighs physical contact in the nurture of youngsters.

Of those who felt that pregnancy was a possibility several nevertheless had concerns regarding the upbringing of the child. For example one said,

*The child's life might be hell – it may have a really poor background and bringing up and stuff but as well the child might end up going into a care situation a care home or foster care or something but I think you canna really decide on that until you you know that the person's no' coping and the child will have to go into a care setting.*

One however was not of this view and 'flack' can come for any number of reasons.

*How the child's life might be [exhale] ..... As in having a learning disability parent for a parent? [Mmhm] I think ..... I dinna think it would be negative or positive – I think it's just what you make it really [mmhm] and you can get flack from your parents for whatever reason for 101 different reasons you're going to get flack about your parents if that's the way they want to go [mmhm] – but it doesn't need to be negative – I don't think it would have to be negative.*

As was reported in Case Study 5, May explained the impact on non-learning disabled offspring of learning disabled parents. The rights of the child were felt to be a major consideration and this links back to values where it is perceived that to have learning disabled parents might be less valued than to have non disabled ones. Additionally there was concern that children born who were not learning disabled may eventually become developmentally delayed. One of the reasons for

this belief was that potentially they could be limited by the ability of the parent/s to stimulate them as the children's intellectual ability surpassed that of the parent. One recent recruit to care services considered the high possibility of genetic conditions being passed on when she said,

*I don't know because somebody who has a disability - is the child going to have a disability so it's maybe no such a good idea and would they be able to care for the kid or stuff like that .....*

- Some types of abuse are worse than others.

To consider which type of abuse is worst in the views of staff it is necessary first to know what they define as abuse. Initial thoughts for a small number of informants focused on self abuse, substance abuse, racial abuse and discrimination. With the exception of discrimination the others carry the suffix abuse and this was also the case with others identified during interviews. *For example* sexual abuse, physical abuse, verbal abuse and psychological abuse were mentioned spontaneously but neglect, human rights infringement and bullying and harassment were mentioned less often and for many only following prompt.

Typical responses were: *Mental, physical, sexual, neglect 'cause that's a form of abuse ..... that'd be it pretty much and Well there's mental abuse, physical, sexual, and ..... mmm I think that would be the three main ones we would be worried about.* One informant stated that abuse is *any treatment that is unfair or any ill treatment towards a person which is unjustified.* Another felt that offering too much choice to a person with learning disability was abusive. This view was not expressed by any other informant.

Another isolated response related to people with learning disabilities who abuse. This informant said *spoke of child abuse where the abusers are people with learning disabilities.*

Several informants expressed views that people with learning disabilities abuse others. An example of this from practice was offered by one informant.

*One resident taunts another by saying 'your mam has died' and though it is true it nevertheless upsets her. When the perpetrator of the emotional trauma is asked why she has done that she says she doesn't know and will never do it again – but she does.*

The repetition of the behaviour would indicate that the perpetrator got some

gratification from the behaviour.

Other examples of this type of behaviour included *abuse happening between service users. If you have a group living environment with maybe someone who is very challenging and maybe someone who is obviously not as challenging and is very vulnerable and they may be dragged up out of chairs or their food taken away from them by other service users and it's not managed very well by the staff*

Thinking about vulnerability and abuse seemed particularly challenging for one respondent. Nevertheless she still wished to continue with the interview. When asked to define different types of abuse she said,

*Em .... God this questions are hard .... Em I dinna ken .... I suppose doing things that they are nae wanting to do or being pressured into things they're nae wanting to do – ken fit I mean? [Mmhm] It's like I ken fit I want tae say but I canna say it.*

One commented *Abuse to me is unfair treatment of any kind and it can take many guises you know whilst another remarked There's heaps of different abuses em there's verbal, sexual there's heaps o' different abuse em there's psychological there's all different categories. And following a prompt financial - yes that's another one.*

Physical and sexual abuse were mentioned by almost all before they considered other possible types of abuse although verbal and psychological abuse were also frequently listed. *Well obviously there's the obvious ones that are related to sexual abuse, physical abuse and those were described by two as the biggies.*

*Well you've got physical and you've got verbal. That's the main two that I can see. Verbal abuse is if somebody is speaking to a person in an ill mannered way.*

One informant who only mentioned sexual abuse and physical abuse initially was then prompted regarding verbal abuse and she remarked *mmm I missed out verbal although it's maybe one of the biggest. On reflection many were of a similar view for example:*

*...verbal abuse in terms of - you know? - inappropriate ways that people talk to people and that again could be on a scale you know all out scale abuse and name calling to maybe just derogatory terms or maybe not communicating with anybody at all other than giving them an order.*

One drew attention to the fact that abusive behaviour can be overt or covert and



though that can be the case with any type of abuse she related it specifically to verbal abuse.

*Abuse can be anything from verbal – verbal abuse – I would say verbal abuse more in this form of work [mmhm] I would definitely say that because you can get the verbal no matter where you are – someone can shout something at you but some other kinds can happen more discreetly – I think in some cases that’s how I would categorise it [mmhm] It’s all done behind closed doors or where nobody sees it ...*

Another spoke of the dilemma for staff when they feel the need to be firm with people, expressing concern that it may be misconstrued.

*... if you speak harsh or sharp with someone and it can be seen as abuse even though you don’t mean it to be because you are using it in a certain context - somebody else could come in and think you are being abusive to somebody.*

Physical abuse was described as *just rough handling or where there’s physical intended harm- you know pinching, punching at whatever scale*. According to one informant:

*Physical abuse would include sexual abuse [uhu?] em somebody hitting somebody em just physical abuse .....*

Following a prompt about psychological abuse one said *that’s one you don’t tend to think about isn’t it?* whilst following the same prompt another admitted he had overlooked it but acknowledged *Yes, you can stir someone up in a way that is really cruel*. Some saw psychological and emotional abuse as the same thing whilst others viewed it differently. For example one remarked *I think that [psychological abuse] would come higher than emotional abuse and again that could come from family or friends or it could be other people in the community*.

*Psychological or emotional abuse would include verbal .....* On the issue of emotional abuse one was very thoughtful and responded *[pensive pause]..... I think that depends on the level because I think you can keep it in yourself for so long and then it comes out*. She clearly felt that the victim may suffer in silence.

Financial abuse was not considered by any informant before being prompted and even then some felt that it would have less impact on the individual since they may not understand it has happened. One suggested *yes I suppose it might be [abuse]*. Furthermore in comparison to sexual abuse where the victim may be damaged long term, a couple of informants felt that even if they did understand they might feel

ameliorated by recompense following discovery of the abuse. For example one commented *Money is only a token* and he elaborated,

*... I think if I lost £10,000 I would be gutted but I would get over it but if I had been raped I suppose in the fullness of time I would but .....*

As his voice tailed the shrug of his shoulders indicated he was unsure of recovery in the fullness of time.

Another provided an example where there was no recompense and not even justice through the legal system which she saw as an outrage.

*There was a client in the community that one of my friends was working not with the person but with a group and one of the carers financially abused this person [mmhm?] and it wasn't just a couple of hundred pounds it was into the thousands [mmhm] and their workplace had, I presume, found out about it and she left without – I don't know if they'd given her references but she's now working with more people with learning disabilities [So she continues with no police record?] Yep – which is shocking when I think they knew what she had done – I mean why was there no charges brought against her? [Mmhm] It was her money they had taken [ mmhm - and it also means you can't rely on Disclosure Scotland?] mmhm, mmhm well it was never reported so how would they ken [mmhm] They are quite vulnerable from some carers who have never been checked again [mmhm That's a very interesting point (name of informant)].*

Informants from the Local Authority provided more detail about this type of abuse.

*... financial abuse in terms of people – yeah they [people with learning disabilities] may have [financial] benefits but actually they never see them [mmhm] because the money's taken into the family or whoever – to the carer's bank account and that person never has any money of their own.*

Even after careful consideration most respondents failed to see any link between human rights infringements and every day practice in care settings. One informant captured what many others pondered when she said:

*Obviously some of them do have – the basic human rights....but as I say there's certain human rights probably – I'm not even aware of some of mine [mmhm] but even if they were being abused I wouldn't know it – they're not really affecting me as I am [mmhm] and I know there's the basic human rights [laugh].*

This lack of clarity was evident across all interviews and the following comment is representative of a number of informants qualified in health or social work.

*You need a fairly robust definition of human rights before you know*

*when they are being abused or not ..... and maybe I've got a picture in my own head of what constitutes physical abuse, sexual abuse, but don't have such a clear picture of what actually constitutes human rights.*

One unqualified health worker had considered the impact of meeting one person's needs when it is as opposed to another's. She stated,

*.... they do something to help somebody's human rights and they might be infringing somebody else's human rights and then we've got our own human rights to think about as well. So they're all infringing on our human rights and we do it as best we can. But then because of the set up and the service you can't tailor to everybody's human rights but I do see we are abusing people's human rights all the time but .....the way things are we can't actually change that.*

Although she did not say so she was clearly demonstrating that she thought human rights were all absolute rights.

Another informant referred specifically to degrading practice but she felt that this was not done with malice. Rather it was done as no other strategy seemed to bring about the desired effect.

*Degrading practices, sanctions and reprimands are commonly used to 'encourage' service users to do what staff want or think best. I think they look at it as getting the job done. They know it's not right – they wouldn't do it in front of me but I don't think they think they are degrading people – just getting them to do what's needed or what's best.*

Bullying and harassment was viewed from different perspectives for example one said *I would categorise that as risk and if I was doing risk assessment .... I could combat that more so than abuse.* In this statement the informant did not see bullying and harassment as abuse. He added,

*I think because we come across it more often [mmhm] maybe we come across bullying quite a lot [mmhm] and harassment and people with learning disabilities are bullied by neighbours and friends in the community and we do do something about it and we don't see that as abuse but as something we see every day . That's maybe a kind of mistake saying that ..... but it could be classified as abuse.*

Considering bullying one person responded *I suppose I was thinking – you know, that coming under verbal abuse* but she went on to say *I have seen that in my time in practice and people being ..... because they are maybe difficult that they are bullied into doing things that makes life a bit easier for the staff or for the carers or the parent.*

A Local Authority worker who sees both family settings as well as care settings felt that bullying is more likely to be prevalent in the domestic family settings than in paid care settings.

*Em I think bullying is probably more in families than services now [mmhm]. I think there is kind of training for the services whereas I think mother's more likely to give somebody a clip around the ear because they haven't gone for the plate of biscuits or ... Do you know what I mean? [Mmhm] and em so I think they probably the bullying and harassment types are more relevant to within families than within care organizations.*

Whilst bullying is reported in family homes and by staff in care services there is also bullying between people with learning disabilities as one informant reported.

*Bullying is very much abuse and you come across everywhere strong people who are used to getting their own way for many years because they demand it, because they are more aggressive than anybody else is and they get their own way at other people's expense.*

One informant made an impassioned plea when he said,

*Bullying and harassment should not go on. I just think it's horrible for residents/clients to go through that [mmhm] especially if a client ... if a member of staff is picking on a client and that client may have non verbal communication and can't express his views or basically 'Go away and leave me' and then they just withdraw.*

Essentially informants felt that this type of behaviour is due to power imbalance. Speaking of the impact of the power imbalance between staff and the people they support one said,

*Then coming back to my own made up definition of power imbalances, there very much is a power imbalance there if you know that if you say something that somebody is not going to like and they are going to shout at you you are much less likely to do it, you are much more likely to not put forward your own views if somebody is a bit of a tyrant, so that is a use of your power to intimidate somebody else, which would very much be abuse.*

Like bullying and harassment neglect did not readily come to mind for most people during the interviews and only after prompting was there further consideration as to whether or not it constituted abuse. One of the few who did identify neglect as abuse without the need of a prompt had worked across the care sector therefore had perspectives from different settings. She said this would include,

*... just not doing the things that people need to just maintain their basic – again on a scale – even somebody who's incontinent for example sitting in their own urine through to people just being ignored because*

*maybe they're a bit challenging or they don't interact .... so I would see that as neglect and obviously on the scale of neglect just people maybe living out in the community just locked in their houses all day because you know the parents have got to go to work and there's no-one to care for them so that would be neglect.*

One informant felt *if you're not looking after somebody it could come under the abusive umbrella.* Likewise another thought *Yeah I would probably agree that that would come under the bracket of abuse of some sort.* He added,

*... if the person has been neglected by their parents or even by their support staff not doing their job in some sort of way [mmhm] that would be kind of detrimental to the person in their day-to-day life so yeah that [neglect] is a form of abuse really.*

Someone of different ethnic background interpreted neglect differently *neglect is not abuse.* Neglect was seen in this context as ignore.

*There are times when one of the residents is very repetitive in her speech. If she is ignored for a short while that particular behaviour stops. It is not abuse and is only done for a short while.*

Following the prompt one informant was quite emphatic that neglect is abusive and provided an example from his experience.

*[Name of Organisation] who have a fantastic name and this particular lady that I was helping to look after needed two to one support and my shift was from 10 o'clock in the morning until 8 o'clock at night and we had went out for a walk because she thoroughly enjoyed a walk but I was told that when she had had enough she would just sit down on the ground and give herself some time and then she'll stand up and start walking again so we took her out for a walk and low and behold she had got far enough and down she went and sat down and it was after a morning of pouring rain and the ground was absolutely soaking. When we got back to the house I said to the key worker – did she want a help to change her ..... she said 'No, no, no, no, no – it's quite alright I'll do it later' Now bearing in mind that this was 2 o'clock in the afternoon and I went off shift at 8 o'clock at night and that lassie still hadn't been changed .... that to me is neglect [mmhm. Was that in recent times?] Oh it's not that long ago – um I would say that's within the last 5 or 6 years [late 1990s] - I'm sure it happens in other places.*

Respondents were asked to consider which, if any, abuses were worse than the others from personal perspective and then to consider whether or not they felt people with learning disabilities might feel the same. A few stated *any type of abuse is bad .....* One who was of this view went on to say *Psychologically I think it's really bad because you can scar that person for life ..... sexually – again you can scar that person for life ..... so they're a' bad but there are some that are worse than others.* Another felt *they're all the same cause you're*

*doing something that you shouldn't be doing.*

Some were quite definite that there were some types of abuse worse than others and contact abuse, at least initially, was viewed as more damaging than non-contact abuse. Sexual abuse was named by several informants and one admitted that the view expressed was influenced by personal experience but still wished this to be recorded. Others also felt that sexual abuse was definitely worse than all the rest and as one explained *I suppose the real taboo for me and for most folk is the idea of sexual abuse [mmhm] I find that very, very abhorrent. Also emotional abuse can be very destructive over a period of time.* However one seemed to have a notional scale in mind when he said *Em, I would think sexual abuse would be a bit worse than being a bit lippy with somebody.* A notional scale was also on the mind of another who ranked a number of different abuses.

*I suppose it goes from your most mild – em ..... sort of verbal abuse, losing your temper with someone, shouting at them, you know speaking to them in a derogatory way right up to your - sort of physical, your sexual abuse, but then you've got your financial as well, it's a wide range that can be lumped into that category.*

One started out by saying ..... *I think they are all as bad as each other* but she went on to say *Em ..... I suppose ..... the one .... Sexual abuse is a big one.* Another offered a view in some way contrary to the preceding one when he said *A lot of people say sexual abuse is the one but if you are getting verbally abused day in day out constantly then it's nae as easy to say which ones would be worst.* This introduces the concept of frequency as well as severity as an influencing factor. Some considered the likely effect on the person on the receiving end of abuse whilst also presenting their own views as to the severity as the following example shows:

*.... obviously, your physical abuse and your sexual abuse, that's really at the top end of the scale, but mental abuse, emotional abuse can ... have just as much an effect on a person as that as well, you can strip away somebody's self esteem and their confidence. You know just by the words that you use when you are speaking to them*

A thoughtful response was offered by one who remarked *it would be a personal thing wouldn't it? – about how bad – I mean if I was to make a judgement it would be a valued judgement on what I would believe would be the worst but it wouldn't necessarily be for the person. It's .... one person's worst nightmare ...*

One felt that one type of abuse seldom happens in isolation of others. She was

referring to financial abuse and though she felt it would be less damaging than some others she stated,

*I suppose if somebody's being financially abused there is a good chance they are being neglected as well. There's a good chance there's some other type of abuse going on so it's very difficult to say those are worse.*

Whilst considering whether or not those with learning disability might be in agreement regarding which is worst one informant felt *They would probably view it differently* another felt *it would be down to the individual*. Lack of appreciation on the part of people with learning disabilities that they had in fact been abused was highlighted by a number of respondents for example one remarked *with learning disabilities they don't understand what the people are doing to them is wrong*. Recognizing that this is the case, one referred specifically to those who did understand however she indicated that their [people with learning disabilities] response was to conform rather than incur further wrath.

*I think ..... the people I have known and worked with who'd understand that concept have said to me that ..... they [staff] have such a big influence on that person's day and how they're made to feel and there are retributions, mainly psychological but people are left feeling 'I'd better keep in with them' you know and I think that that's really sad.*

Another drew on her experience of services in which there had been abuse but she felt that the people did not appreciate that they had been abused.

*I'm not sure. Again it depends on how bad the disability is but I think they're aware of it ..... I remember I worked somewhere else and there had been abuse that had gone on but the clients weren't aware that it was abuse and this had gone on for a long, long time but the clients weren't aware that it was abuse and I think that's really hard because I have never really dealt with it so I dinna ken but definitely the clients weren't aware that it was abuse.*

This is an important point since there may be no attempt on the part of staff to provide support for people who are abused however if they did not feel abused to begin with, enlightening them to this might be more damaging than the actual behaviour that is deemed abusive by others. According to one informant,

*They're not aware that this is wrong and that this shouldn't be happening so to an extent as well when you're taking them away they think there's something wrong .... they don't understand it in the same way as you and I would.*

She was referring to the situation when a person is taken into care for safety reasons and removed from their family and their negative experience according to her is the removal from close family rather than what has been considered abuse or a potential abusive situation. She further illustrated this with an example from her practice:

*There's two or three people we're involved with that've been abused by their families and things like that and then they see this great big punishment that we are not letting them go home and we're not letting them do this and we're not letting them do that but it's not that we're punishing them – we're trying to protect them and they don't understand that - they see them as that's their relatives and they love them and it's their family and it doesn't matter what they've done ....*

One informant had supported a lady who had been sexually abused and though she could only speculate she imagined that that experience would have influenced her thinking.

*I think she would definitely say the sexual abuse although she was quite emotionally abused as well but I think it was the sexual abuse that stood out for her.*

One spoke of the misery with regard to frequency versus severity and it left her unsure if people with learning disabilities would share her views. She felt that if people with learning disabilities were subject to *a lot of verbal abuse and being put down constantly by anybody* they might instead feel that one slap might be preferable to the ongoing misery.

- Lack of education leaves staff/carers at risk of adopting an approach inconsistent with the principles of the organization.

According to one informant *when you are working for a big organisation you take it for granted that there would be abuse and there would be situations that vulnerable people might be taken advantage of* but he felt that *it would do no harm to bring it [policy] to their [staff] attention now and again*. A common theme was that policies are too complex, use too much jargon and are not easy to understand and several felt there would be advantage in discussion regarding the detail. As one informant said,

*Some of them can be quite difficult to take on board sometimes. I think, if you are coming into the service and you have got no background of working in the care service, then I think the way things can be worded sometimes can make it difficult to get an exact idea of what has been explained to you and I think it is beneficial that you've got people who have been there for, you know, X amount of years and they've got the experience that could maybe sit down with the person and explain it to*



*them and explain exactly what is meant by what is written down.*

*Sometimes the terminology used and words and language used are difficult if we're only handed a policy to read. I think I would probably miss things or misunderstand things. I think things need to be explained* was representative of many of the informants in this study. One who worked in the independent sector explained how staff have little time to read policies and many do so during their meal breaks in the only free space – the staff tea room. He explained,

*Take this sector which is a money making business for some people, for the owners and down the line a bit, they want to put as little as possible to get as much as possible back out [mmhm] so they actually don't want us to spend a huge amount of time on these type of issues – issues they are concerned with are moving and handling properly because by law they've got to be able to do that.*

The implication here was that adult protection was not seen as law whilst staff training on moving and handling of people was seen by him to be a requirement of law. The latter he felt was more likely to result in litigation through staff who could claim a work related back injury than abuse that people with learning disabilities might not be able to articulate.

Speaking of policy one related this with the need to read and associated it with theory. As he explained some staff do not see this as something they wish to do.

*I think eh - people don't always make an attempt to understand it. People really - I think there's an awful lot of folk within care in all sorts of different sectors - they have very little time for theory. They see themselves as practitioners that are maybe doing practical things, [mmhm] very good at basic care giving, very good at supporting people, but say theory is something outside where they are at and what they are about .....*

Another who was of a similar view explained how difficult it would be to be forever conversant with all relevant policy when he commented *Policies change one helluva lot – virtually month in month out and it's very difficult to keep on top of them. I'm not having a pick at people who are lower down the pecking order but they see themselves as ' Oh that doesn't relate to me – that's people who are higher up the ladder and ... whereas we are all working with people with learning disabilities.* He added,

*I don't want to sound big headed but we, who are higher up the pecking order, do try to keep on top of things by reading and manuals who specialise within the learning disability side or perhaps – I get 'Care and Health' delivered on a weekly basis which doesn't only deal with learning disabilities but it does make you aware of changes in*

*legislation.*

On this issue he concluded *they seem to think to themselves 'Ah my job doesn't really revolve around that so I don't need to know that' which I think is wrong.*

According to another *they [staff] learn the policies, they find out what it's about we audit that they've got the gist of it but then putting that into their practice doesn't necessarily flow as you think it would because it's about their basic values and attitudes towards something.* Values and attitudes strongly influence care. Indeed all of the respondents indicated that they were more influenced by their own personal and family values than on any policy they had read.

Specifically relating to policies on vulnerability and abuse one said *the council do run training days ... but I think different organisations that might be kind of smaller organisations don't have that money to train their staff and support workers or homecare support workers and I think there is a tendency to just get staff in there to be present and to support the client and then actually forgetting why they are getting that support.* This mirrors the view expressed by Marcus (Case Study 1) where lone workers often experience difficulty being released for training.

One who had recently returned to care work felt she was inadequately prepared and she highlighted why she felt this was so when she stated *It's difficult with all the reading and nae everybody has the time because we are told 'Here's a policy and you have to read it'. And like there's pages and pages. To me – it's kind of – if you weren't trying to do so much at once because when you have to read and read and read you come to the stage where you canna read nae mair.* She went on to say *I think if someone sat down and told you cause you're inclined to take in more if somebody's telling you rather than just reading.*

Another, who was a long serving member of staff, had experience of many changes of legislation and policy and she felt that *policy would only be stating so much and there's a lot, lot more could be going on and happening but you could probably not write it all down either.* With regard to vulnerability and abuse she felt that no policy would ever cover *every possible way that somebody could be at risk of being vulnerable. It's amazing how low some people will go and you could never imagine ever in your own mind sadly.*

One local authority worker felt that, in general, care workers are not given adequate training regarding policy and consequently he felt they were ill prepared

to discern when practice could be improved. He illustrated this with an example.

*I think you could spot that sometimes when you go into organisations and they're laughing because Joe Bloggs is in the toilet wi' somebody and they're kind of laughing about it [mmhm] you know? They shouldn't be allowing that to happen and that needs to be reported and that needs to be investigated – you know? Why has that situation happened?*

- Family and personal values are a greater influence than policy.

A couple of informants suggested *just treat people like you would like to be treated yourself* and this is clearly a valued judgement however as was reported in Case Study 3, April felt this was not the best maxim on which to base care. Family and personal values were very strong influences for all of the respondents in this study. This was evident in the views expressed by one informant when he said *well obviously you're - well hopefully - you're brought up with the em ... a good instinct for right and wrong. Em ..... but I think you hopefully learn your good practices through the policies and procedures that are set in place, em, to protect your patients from abuse.* Another who shared this view added:

*I think sometimes it is quite hard to challenge your own values and your own beliefs [mmhm] but when you do work with people who have got experience and that, you can look at things from their point of view and you can see things that you've maybe missed before.*

One explained that she had based her practice in the past on policy and procedures but since she became more experienced she had shifted back toward being more influenced by what she believed to be right based on her values.

*Before it was more the organisation –if they told me then I would do that and that was just what you went along with – someone came in and said do this so you just did it but now knowing and being in the job as long as I have I think 'No that's not acceptable' and if it's not acceptable for me then it's not acceptable for the person I'm looking after so I do put my points forward quite a lot.*

She went on to explain that she would now challenge anything with which she did not agree.

*... some of them - the policies of provider are in line with my own views and some of them aren't - but if I was reading a policy and I had problems with it then I would go higher and say 'I don't think this is right – why are we doing this?' I would question it.*

One confident individual explained how he felt his upbringing and his own developing values base have influenced his care.

*I've always developed my own views and sometimes they have been in*

*line with the organisations that I'm working with, so they've been personal views that have been shaped by education, that have been shaped by my own kind of reading. I think my views have been shaped an awful lot by an understanding of where I kind of came from, I cannot believe sometimes still how naïve I am. I came from a very stable family background and my mum and dad are still together. I had a very nurturing healthy background with both parents around and grandparents and extended family, very close by.*

Another clearly felt that he had to work in discord with what he believed to be right in some instances nevertheless he did convey an impression of acceptance of corporate values, policies and procedures.

*That's a difficult one because um ... I would like to say that I work to my own values but there are things that I might have to agree to because of organisational policy that are not in my own personal values [mmhm] but I can't let that cloud what I'm doing professionally [mmhm] When I go home at night I might ponder the fact and think 'now if that had been me I might not have done that' [mmhm] but I've got to work to these policies and try and not let my values cloud these.*

Reflecting back on her early experience of people with learning disabilities she stated *I think I probably had leant more toward pity than I do now* but she explained that her thinking had moved on from that position as she explained,

*I think now that that's less so ..... at one time I probably thought not about people being able to have families and jobs and it would've been more to wrap them in cotton wool but as I've worked more in service and see the possibilities for people you know my views has changed.*

On this issue she concluded:

*..... one of the ways my views have changed is through education and through learning [mmhm] em moving from medical model to social model you know*

Another recognized that her *values are very different to everybody else's* and she felt that people need to be aware that their values may not be the same as those of others so she cautioned against assuming that this is always the best measure.

One who stated *personal values is a lot to do with how I carry out my job* felt that this would also be *how other social workers and care staff do carry out their job. In addition to personal values though he felt that personality* also influenced care given and he pondered *I think if we never [took our own values into care] we'd all be the same.* Family values figured significantly for one whose parental experience also shaped the care she gives.

*I think I have always had similar views but they have changed as a result of education and also bringing up my own family. I sometimes*

*treat the men as I do my children and I sometimes treat my children in the same way as I might treat the men [laugh] I have never shouted at or hit my own children.*

One who felt that he was most influenced by his personal values rather than his organization said he incorporated quite a bit of himself in the attitudes he holds indicated *I would say 80% is my own attitudes and 20% is like the local authority.*

## CHAPTER 6 DISCUSSION

### 6.1 Introduction

In this chapter the findings of both the case studies and themes are discussed. The aims, objectives and research questions identified in Chapter 1 influence the nature of this discussion in which the range of meanings of the terminology used in relation to vulnerability and abuse is considered. Additionally consideration is given to the impact of power on those concepts.

The strengths and limitations of the study are discussed and new knowledge emerging from this study is highlighted.

### 6.2 Vulnerability - '*Danger need not spell disaster*'

At the outset of the study the intention was to investigate interpretations of the terms vulnerability and abuse within learning disability services. However it emerged early in the data gathering phase that notions of vulnerability seemed elusive to respondents. Furthermore there was added complexity when they went on to consider the meaning of being 'at risk'. For some risk and vulnerability were synonymous, for some they were very different concepts and for others two ends of the same scale. It is not therefore appropriate to consider the concept of vulnerability in isolation of risk. Instead they are considered for their similarity as well as their contrast.

Within this study all informants associated vulnerability with some other factor. *For example*, some associated vulnerability with risk, some with particular care groups, yet others with abuse and some in relation to the broader concept of being human and existing in a world where people are affected by the environment in which they exist. Indeed it is necessary to consider vulnerability as a dynamic phenomenon; interactive with the individual and others and with other environmental factors.

Labelling of people is widespread and people do this to make sense of their world; who they are in relation to others. Every individual fits many different descriptors *for example* wife or father describes an individual in relation to others, worker, club member, traveller, *etc* describes him in relation to social roles and patient, client, *etc* provides a connection in relation to services accessed. The literature indicates that more valued roles include employee,

manager, professional whilst less valued roles include service user, person with mental health problems or learning disabilities. In this study informants felt that the balance of power was in favour of professionals, managers and employees thus it can be deduced that power is with those with the valued roles. Whilst this balance was felt necessary by several informants a consequence of power imbalance is the disempowerment of the individual, in this case person with learning disability, which in turn may leave him/her feeling vulnerable.

Even though several informants felt an association between labelling and stigma and consequently stated aversion to labelling practice there was for them a conundrum when they attempted to describe the service they provide whilst avoiding the use of such labels. Each informant was selected for this study because they supported people with learning disabilities including those who might fit more than one care group such as learning disability or older people. Clearly to address the issue it was essential that the support staff (the informants) were defined in this way. Some implied that in attempting to address the equality and diversity agenda it is not possible to use labels comfortably even in a positive way to provide specialist enhanced services only available to those in the category. Instead, staff attempt to meet the requirement of policy or the preferred approach of their seniors in their respective organisations even when by so doing they feel they are acting against what they themselves believe to be right.

In general terms people with learning disabilities are relatively powerless when compared with non-learning disabled people. Yet several informants reasoned that the label does not necessarily result in the individual who is learning disabled being vulnerable although several who felt this way came full circle in the argument concluding that perhaps the label exposes vulnerability even if the individual him/herself does not feel it.

The majority of informants felt that people in particular categories or care groups were more vulnerable than others in society. *For example* several categorised children as vulnerable as well as people with learning disabilities and a few identified elderly people. Despite this, most felt that there were some people who carried particular labels who were able to assert their own views thus it can be deduced that there is a perception that they are comparatively less vulnerable than others within the group. Accordingly, it was in personal strength and confidence or absence of it rather than the label that people were deemed to be more or less

vulnerable than others. Surrendering power or having it taken away leaves a person exposed and possibly feeling vulnerable however, as some informants pointed out, on occasions people with learning disabilities reclaim power and assert their position and sometimes this is not always to good effect. As some pointed out there are occasions when they use that power to bully or abuse other vulnerable people and in this regard they can fall foul of the law and acquire the label 'offender'. It is unlikely that whilst feeling powerful they are simultaneously feeling vulnerable.

Though most found it extremely difficult to define vulnerability they did nevertheless feel sure they would be able to recognise it. Indeed, as was reported in Chapter 5, children are able to recognise this complex phenomenon. Informants also indicated that learning disabled people can recognise vulnerability as some become abusers hence it is reasonable to assume that, like other abusers, people with learning disabilities choose their victim based on a judgement of weakness or vulnerability. In shared living settings such as hospital wards or care homes this can create a pecking order where abuse is possible.

Because it is felt to be so easily identified the risk to those who feel vulnerable, or who are considered vulnerable, must be intensified if those who would prey on and exploit people who are so defined are also able to spot it. This exposed position in which some people with learning disability live their lives provides opportunity for those who would choose to abuse them. The stage is then set for those who might act out their intentions and groom people. The findings of this study indicate that people with learning disabilities can spot vulnerability and exploit it therefore it could be reasoned that in so doing they get gratification from that behaviour. This creates a power imbalance within the community of people with learning disability. It was even acknowledged that, though less prevalent today, staff do not always intervene when they should *for example* one care worker highlighted a recent situation where two people went into the toilet together and staff failed to take action.

Some informants suggested that with increased education staff may become more able to recognise vulnerability however this is inconsistent with the views of others who held the view that people with learning disabilities and children can recognise it and this recognition is not generally based on any particular education or definition. Indeed there would be some inconsistency between this



view and the notion that vulnerability has a dynamic component in that each situation would be judged on its own merits. Moreover in addition to a learned component to recognising vulnerability there is also an instinctive component. Nevertheless a significant number of informants felt that education would enhance understanding provided the education took the form of facilitated discussion rather than a lecture approach. As several informants indicated that they had not considered this subject deeply prior to the interviews, the discourse during interviews may have heightened awareness of the need for increased understanding.

Inability on the part of learning disabled people to understand what is happening to them, communication barriers and inability to protect themselves were seen as factors causing vulnerability. In this view of vulnerability, it is others rather than the individual concerned who decides on the vulnerable label or the degree of vulnerability.

It was felt by many that there was a strong correlation between dependence, powerlessness and vulnerability. Neediness and reliance on others were also seen as conditions that predispose people to vulnerability. Though it was not always clear in the narratives of the informants, the aforementioned states might be felt from an individual perspective or conferred by others. None of those states would be desirable ones. It might therefore be deduced that the preferred states might be the opposites such as self reliance, personal control, autonomy, etc.

Whilst considering definitions of vulnerability it was clear that informants considered people with learning disabilities were more or less vulnerable. Although informants were not specifically asked what might be the desired opposite state from vulnerability some volunteered that those who are 'less vulnerable' *have it all up top and don't see themselves as vulnerable*. Nevertheless they it was evident that they did not feel all people with learning disabilities are vulnerable to the same extent. If they are not vulnerable then it follows that an alternative applies. Clearly therefore there is appreciation that definitions of vulnerability differ based on individual perspective. This is likely to lead to variable application of policy if the definition of the term lacks clarity.

There is no ready antonym that adequately conveys how an individual might feel if not feeling vulnerable. From an individual perspective one cannot feel vulnerable whilst simultaneously feeling confident even though in one instant

he/she can feel vulnerable whilst in the next instant confident. Indeed to take this one stage further the feeling of vulnerability from an individual perspective is not usually a permanent state otherwise it would be accompanied by feelings of complete despair thus improving ones position in this regard must be accompanied by optimism and hope.

Even the individual who is supremely confident is not forever at the pinnacle of confidence. Rather he/she may feel less confident, even vulnerable, in situations in which there is little familiarity. Whilst some might describe those who are disenfranchised as more or less vulnerable rather than somewhere along a continuum of vulnerability to confidence it would be reasonable to assume that if this state was personalised few would say ‘I feel less vulnerable today’. Rather the improved state would elicit a more positive response – ‘I feel more confident today’.

It is argued here that there is a certain rhythm to feelings of vulnerability and confidence and this is conveyed in the following model (Figure 6) – a wave like impression that represents the effects of different experiences (both positive and negative) through the life span. With early recognition of vulnerability support can be offered that in turn can create hopefulness rather than feelings of hopelessness due to the improved support or due to feelings of increasing control in the individual’s own life. As the individual feels empowered therefore he/she may increase in confidence.

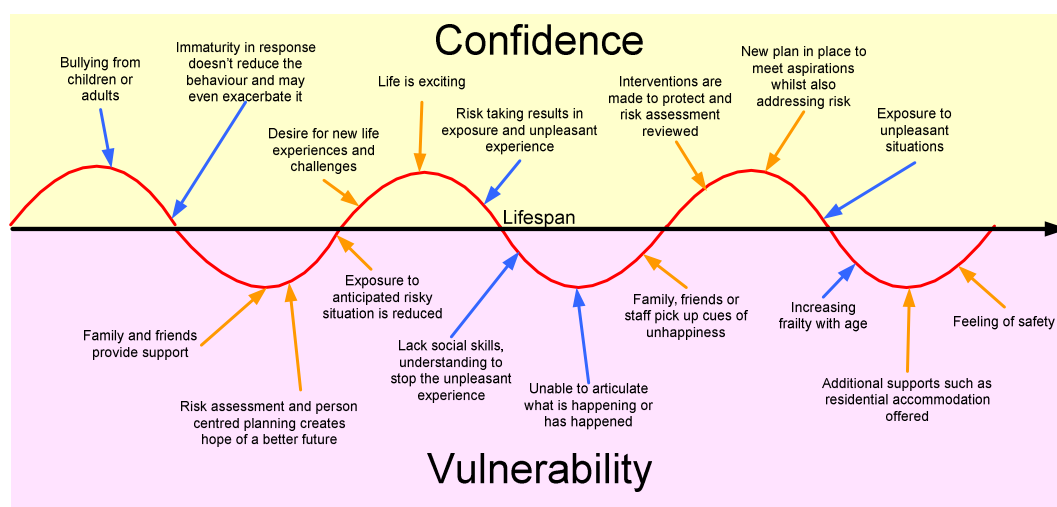


Figure 6 Model of vulnerability to confidence and the impact of exposure to risk and available supports along lives journey.

The majority of informants associated vulnerability with perceived conditions *such as* communication difficulties, lack of understanding or inability on the part of people with learning disabilities (or any other so called vulnerable group for that matter) to protect themselves. Fewer associated it with the feelings of the individual yet when considered from a personal perspective several commented that *we can all feel vulnerable*. Thus whilst they considered their own experience in terms of feelings they viewed vulnerability differently in relation to their support role. Whilst only they were the judge of their own degree of vulnerability they felt able to decide on the degree of vulnerability of those they support. Moreover, no informant conveyed a view that if there was sufficient concern about someone deemed vulnerable, even though he/she did not consider him/herself vulnerable, that supportive or protective measures could be put in place regardless. This introduces another dimension to vulnerability for those labelled 'vulnerable' since they may not be able to take the same risks as other citizens if their wishes can be over-ruled by staff acting in what is perceived as their best interests or out of duty of care.

A number of informants viewed vulnerability and 'at risk' as part of a continuum with vulnerability at the lesser end of the scale whilst 'at risk' was associated with what informants perceived as the worst types of abuse. As was reported in Chapter 5 verbal abuse, bullying and harassment, financial abuse and neglect tended to be viewed as softer or lesser forms of abuse. Since being 'at risk' was associated with physical and sexual abuse whilst verbal abuse and even bullying and harassment were viewed as every day events or experiences for people with learning disabilities it can be deduced that verbal abuse and bullying and harassment are associated with the lower end of the continuum: vulnerability. To expand on this it is unlikely that an individual is considered to be 'at risk' from an every day event or experience. Rather it is expected to happen or otherwise protective or supportive measures would have been put in place to reduce the risk. However the findings of this study revealed protective measures were more associated with that which was considered to be greater risks. There may be some correlation between the views expressed by informants in this study and the attention given to sexual and physical abuse in the literature and in the media. Likewise reduced awareness of neglect as abuse may be related to the paucity of research literature or attention in the media of *for example* neglect of people with learning disability.

Lack of social skills was seen as a determinant of vulnerability as were several other risk factors. Indeed risk and vulnerability were used interchangeably by several informants yet the risks were seen in terms of exposure or potential exposure to hazardous situations. Risk was occasionally used in relation to the vulnerability of (sometimes described as 'risk to') the individual in terms of the potential outcome of exposure *such as* 'being taken advantage of'. Vulnerability and risk were linked to external factors such as road safety which could be considered as environmental factors and also to the potential for exposure to predatory behaviour of those who would abuse.

The notion of being streetwise was used to convey increasing maturity. As people mature their right to self-determination increases. There were strong views that when people are not streetwise they need to be protected and this is likely to strongly influence the life experiences of cared for people, in particular in a limiting way, of how they are allowed to live their lives in terms of risk taking.

Immaturity was associated with childhood and some informants drew analogies with their own family experiences in comparison with adults with learning disabilities. The concept of immaturity is an interesting one since some would consider this as childishness. Nonetheless, since introduction of social role valorisation theory service providers and their workers resist association of adults with any connotations of childishness particularly as it is not viewed by service providers as appropriate in the contemporary context even though analogies are often made. But this belies the control that care staff are able to and do assert over the lives of people whilst they also espouse the theoretical stance.

Many expressed the view that people are vulnerable if they are unable to speak out about what is happening to them or about things that make them unhappy or distressed. Communication was also seen in a different light when it was felt that the power of language created a distinction between staff and those they support. This in turn strengthens the position of staff whilst reducing or eroding the position of those they support increasing the chasm between the two. Neediness in terms of reliance on services and dependency also creates a culture where power imbalance can flourish and in this situation there is a likelihood that exploitation and vulnerability may co-exist.

Culture and social status are also considered to be factors influencing perceptions

of vulnerability. Cared for people rely on paid care support within services even though some are supported within their own tenancies or within family settings. Since they are reliant on others for their care and support, cared for people are needy and dependent. This neediness or dependence creates a situation in which there can be a power imbalance and where power imbalance is present vulnerability can be exposed.

Support staff consider vulnerability as it relates to the individual but also the possible consequences for the organisation should a person who is deemed vulnerable and 'cared for' come to harm.

Although literature tends to refer to abuse associated with particular categories of people such as those abused within the domestic setting – domestic abuse or those defined within a particular care group such as child abuse or elder abuse only a small number of informants in this study felt that this had relevance. Most showed sympathy for the view that people labelled within a particular care group that is generally associated with the vulnerability label are in fact vulnerable although there were some exceptions. But even those few exceptions also expressed some feeling toward that view as was indicated by one informant with regard to the cognitive ability of elderly people who may be less vulnerable because they *have it all up top*.

That some informants in this study felt that eliminating risk would in parallel eliminate vulnerability implies that the two are different. However the lack in clarity of the difference between the two or lack of certainty that there is a difference highlights the need for attention to the language associated with adult protection policy if it is to in turn bring change in practice. An illustrative example where an individual may waver between confidence and vulnerability can be drawn from Case Study 4 where May referred to a young woman wishing to go to a disco. In this scenario the young woman might feel confident in the knowledge that she has a plan for her safety however that confidence might waver if *for example* she did not manage to get a taxi home but might soon feel confident and in control again if she was able to telephone a friend for help.

### 6.3 Risk

The concept of risk, and in particular being 'at risk', was seen by many as similar to vulnerability however of those that were of this view most considered being 'at

risk' as worse than being vulnerable. Being 'at risk' conveyed for most an impression of imminent danger. And it conveyed danger at what was perceived to be at the worse end of a scale or continuum. Typically those at the worse end were specified as being at risk of sexual and physical abuse and this is discussed in greater detail later in this chapter.

It's all too easy for supported housing organisations and others to feel that the only safe approach is to avoid risk. Justifying to a funder or local authority your decision to enable clients to take reasonable risks can be tricky. But we have to be willing to stick our heads over the parapet on this issue, otherwise the services that we are providing will have more in common with the simple containment approach of the nineteenth century than the twenty-first century.

(Foundation for People with Learning Disabilities *accessed 12th April 2007*)

Risk is a consideration in relation to duty of care. The concept of duty of care within provider organisations is often seen as a protective measure rather than an enabling one. Hence it is used, and sometimes abused by staff, to prevent people from taking risks that others in society might feel should be avoided by those with learning disabilities – that is to say, they should be prevented from taking the risks that a paternalistic society might feel inappropriate. Thus staff who use duty of care as a rationale for eliminating risk at best can have a clear conscience that they are acting in the best interest of the individual. This is not however a person-centred approach. Rather, it is a professionally imposed plan that pays no cognisance of the hopes and dreams of the individual and indeed could even be seen as detrimental to the individual. Certainly from the person-centred perspective it would be seen as limiting. Yet some informants felt they had the approval of the people they support to take those decisions for them whilst others saw this more negatively - as a mechanism used by some staff to control people.

Duty of care was seen by some staff as a positive support from 'the powers that be' for them to act in the best interest of those they serve. In other words they see it as the authority conferred on them to care even if that means taking decisions for the people whom they serve without their involvement. Whilst there is a dilemma for staff in deciding what degree of intervention is appropriate as was seen in the statements of informants, duty of care for one person can be in conflict of that of another and certainly in shared care settings this is seen as a balancing act as is sometimes the case during episodes of aggressive behaviour. However, with regard to use of restraint to manage difficult situations, the MWC (2006 *pp* 25) caution illegal or inappropriate restraint may be a civil wrong.

They add:

Breach of a duty of care can amount to a civil wrong. Furthermore, it is easier to prove a civil case, in that a wider range of evidence is admissible, and the standard of proof is lower (the '*balance of probabilities*' and not the criminal test, which is 'beyond reasonable doubt')

This is likely to create greater anxiety for staff even though the MWC go on to state that 'the law would expect a risk assessment, a care plan that details the need of restraint and adequate staff training'.

Locking of doors to prevent egress from residential accommodation was seen as a protective measure for those who do not appreciate the dangers they may encounter should they go out unescorted. However the locking of doors during periods of staff shortage was also seen as duty of care although in the latter instance it was considered in relation to the greater good of making best use of limited staff resource to support all in their care. In their document entitled Rights, Risks and Limits to freedoms the MWC acknowledge the realism of not being able to provide sufficient staff in order to avoid restrictions to freedom but they fall short of giving sanction to the locking of doors.

Risk assessment and safety planning therefore should be both enabling and protective. And it should be person centred rather than professionally driven. Recently Alaszweski (2003) (*accessed 12th April 2007*) reported the stages in writing and implementing a risk policy as:

- clear statement of aims: indicating the need for a balance between safety and empowerment.
- clear definition of risk.
- clear statement of the stages of managing risk.

He argues that only by enabling people with learning disabilities to take reasonable risks can we help people reach their full potential. In this regard Alaszweski advocates a person-centered approach to planning and risk assessment upon which a clear decision making process should result in the recording and communication of risks whilst at the same time recognizing the importance of supporting staff following decisions made according to the risk policy that result in less favourable outcomes. This last point is important for staff who feel disenfranchised by the erosion of many of the approaches used

before. This disenfranchised position has come about since a range of options that some saw as available to them *such as* behavioural approaches that have been eroded. Some informants *for example* declared that they were aware of what they could not do but were not offered a number of acceptable alternatives hence they felt 'their hands were tied'. Even though some approaches are viewed negatively *such as* seclusion and denial of privileges some informants saw use of those approaches as consequences. In this view it is easy to see how people who support those with learning disabilities might feel that there is inconsistency in application of normalization theory if people with learning disabilities do not pay the consequences for unacceptable behavior whilst reaping what they see as rewards for good behavior. Nevertheless to consider it in this way without considering more deeply how many (non-learning disabled) adults would have their behaviour manipulated in this way would be a misrepresentation.

For every citizen living is a risky business – that is to say around every turn there are risks and this creates excitement. Some seek it more than others however people with learning disabilities are often denied the opportunity of the excitement that others take for granted because of the perceived bad outcomes. Often staff interpret this as a duty to care.

Duty of care is linked to patient safety and in principle should be a positive concept. However within this context it is viewed as a need to protect and since this may not necessarily be in accord with the views of the individual who is being 'protected' it therefore may not be wholly positive. The legal interpretation of duty of care is not widely understood by care staff although the term is familiar to them. Application of it therefore is likely to be variable with this term being used as a sanitised version of the cosseting approach that some informants felt necessary though they did not describe in those terms. Duty of care is often the reason given for carrying out risk assessment. However risk assessment cannot reduce or remove vulnerability it can only reduce risk *that is* the potential or anticipated negative impact from a particular happening.

Risk is prospective - it always relates to the future. Whilst lessons can be learned from past events that may inform a risk plan they need to be considered in relation to the context of that past event. It is the manner in which risks are assessed that dictate the likely plan emergent from those considerations *that is* how to manage the risk. *For example* June (case study 5) spoke of the young



woman wishing to go to a night club as other young women. The anticipated risk might be sexual or financial exploitation. As evidenced in this study sexual abuse was perceived to be worse than financial abuse therefore in the aforementioned example financial exploitation is likely to be a secondary consideration. Consequently a measure that ensures that she is accompanied by a friend or family member might offer protection from both perspectives whereas providing education about relationships might only address the former in addition to being removed from the context. However being supported by a family member would also create a different social situation when compared against other women of her age.

The aforementioned example takes account of possible stranger danger however it takes no account of danger from those within the individual's close network. Acknowledgement of such a possibility in any individual's situation would almost certainly introduce a prospect would almost certainly bring chaos into the individual's life. Instead assessment of this nature is more likely to be based on some evidence or suspicion this is more retrospective. Yet informants did recognise this as a danger even whilst it was also acknowledged that people with learning disabilities still feel a bond with those who might abuse but on whom they are also dependent. Whilst informants recognised the risks within family/domestic settings they also recognised the risks in paid care settings. However regulation of care workers can reduce the potential risks in paid care settings but family will always be family to the individuals therefore different approaches are necessary. Risk assessment associated with recruitment of people 'fit' to support those deemed vulnerable is more likely to be associated with organisational risk assessment rather than person-centred assessment whilst risk assessment associated with the family/domestic setting is more likely to be person-centred in orientation.

At its best effective risk assessment will eliminate bad outcomes however its effectiveness can never truly be measured since it is only when risk taking goes wrong that the risk assessment is called into question. Thus organisational desire to ensure risk assessment is carried out may be perceived by staff as a corporate approach to limit damage. Indeed that will almost certainly be a consideration for most organisations. In this situation organisational risk assessment is carried out to reduce or eliminate risk (noun), possibility or chance of a bad event whereas a person centred approach might focus on how to implement reasonable

safety measures that enables the individual to risk (verb) an event happening and enjoy that experience as others might. Being in control of decisions about the risks one takes is exciting whilst being 'at risk' is likely to evoke more negative feelings *such as* fear. Risk management should be concerned with reducing negative experience of risk: it should not eliminate the positive experience of risk.

Central to any discussion of risk assessment, must be the recognition that risk assessment should be concerned with enabling people to enjoy life in a manner that takes account of potential risks – it should not be about wrapping in cotton wool and thereby limiting peoples' lives. Moreover risk assessment is not an end in itself but is part of an assistive rather than a resistive process. Further it need not focus on risks that will never become eventualities *for instance* an activity the individual may never consider doing.

The concept of a safety plan rather than risk assessment, where risk assessment is only one part, could shift the emphasis toward a more positive and enabling approach rather than the cosseting strategies where the starting point is identifying and attempting to eliminate all risks.. At the centre of the plan should be the hopes, dreams and aspirations of the individual and recognition of the excitement the risk may bring. Thereafter consideration should be given to that which is not negotiable *for example* service providers would not be able to support a choice that could result in a high chance of death or serious injury and parents may not feel they can financially support an expensive pursuit for their son or daughter that could result in harm. Other considerations should include legal and ethical issues however they should be considered in the same way that any other person would consider them and should not be used as a means to prevent an activity. Rather they should be factors in support of effective development of the safety plan. The safety plan is demonstrated in the model overleaf (Figure 7).

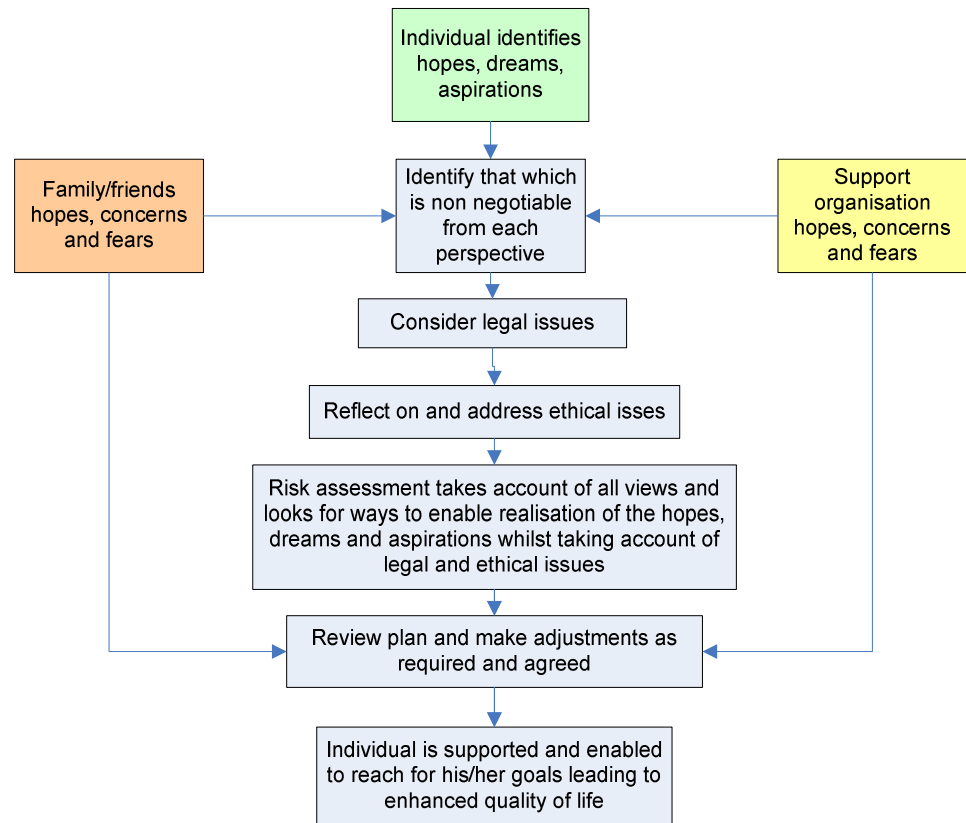


Figure 7 Safety Plan based on inclusive risk assessment

## 6.4 Abuse

As vulnerability has a dynamic dimension so too has abuse. Abuse is an opportunistic behaviour that happens within different contexts – *that is* it only happens if the situation is ripe in terms of person/s (victim/s and abuser/s), situation (environment). If either is blocked then the abuse will not take place. *For example*, if the potential abuse is identified through risk assessment and protective measures put in place *such as* ensuring the person is accompanied in the activity about which there is concern or alternatively the activity being avoided.

What was apparent from this study is that there is lack of clarity regarding what constitutes abuse. Almost without exception informants named sexual abuse and physical abuse, fewer named verbal abuse or psychological/emotional abuse and still fewer named financial abuse or neglect. No-one mentioned human rights infringement. Prompts regarding bullying and harassment elicited very variable responses. Some considered those abusive whilst at the other end of the scale others viewed them as expected everyday events– typical for people with learning disabilities and therefore not abusive. In particular there was a feeling that people with learning disabilities will never be free of bullying and

harassment.

For some mention of abuse elicited notions of self harm (named as self abuse), drug and/or alcohol abuse: self inflicted behaviours that are beyond the scope of this study. Although abusive behaviour can be overt or covert it was felt that mostly it happens out of sight of witnesses. Nevertheless some felt that when it is overt it is done through ignorance.

Several informants used the word *just* (meaning only) to describe some types of abuse such as verbal abuse, contempt, when compared to others described as vicious such as sexual abuse. The use of the word 'just' trivialises and lessens them in comparison to others. In fact, when they considered those same experiences they had described as 'just .....' for people with learning disabilities, in relation to the same behaviour directed to themselves most felt that it would cause them distress. Yet they did feel that with the present culture in society people with learning disabilities are likely to continue to be exposed to this lesser type of abuse they described for the foreseeable future.

Although people observed behaviour of staff that made them feel uncomfortable few felt that they could report a colleague at least initially. Although they did not say so, implicit in their comments was the notion of a particular tolerance level. *For example* being contemptuous, disrespectful, rough handling people or 'being a bit lippy' would be more readily overlooked than behaviour that resulted in visible evidence of abuse *such as* assault. Support staff should be enabling people in all aspects of their lives and this should include enabling them to be safe. If in paid care settings staff feel unable to report poor or abusive performance of colleagues people with learning disabilities can never be truly safe and staff are failing in their duty of care. This is despite the claims that duty of care is a major consideration in risk assessment.

Informants felt that although physical pain may be experienced similarly for learning disabled people and others there was a strong sense that the former were less likely to be emotionally affected by abuse than others. A number of different reasons were cited for this:

- Their values are different
- They do not know what is abusive consequently they do not appreciate they are being abused unless there is physical pain

- Their socialisation processes are different – they are looking for relationships and may be drawn into situations that are abusive through lack of social understanding.

We can understand that someone feels physical pain if they cry out or wince from it but we can never truly know if or how much any individual is emotionally hurt or traumatised by any situation. Communication of very personal emotions is difficult for many people – not only those with learning disabilities but for the latter the difficulty is perhaps exacerbated by communication difficulties. A further complication for people with learning disabilities may be the language that care staff use to describe behaviours that are abusive. It is not the type of language that would generally be used to describe those abusive behaviours if experienced personally. Nevertheless people who are labelled as vulnerable by others are also provided with a different language for the unpleasant experiences they have – physical abuse instead of assault, financial abuse instead of theft, sexual abuse instead of rape or other sexual descriptors. Moreover definitions of abuse proved difficult for informants in this study despite policy documents detailing each type of abuse. Therefore it can be little wonder that it proves difficult for people with learning disabilities to articulate concerns when there different language is required.

Not only were the nature and severity of abuse considerations but the duration over which abuse has taken place came into the reckoning of informants. There was a general feeling that where abuse had taken place over a longer period of time the suffering was likely to be more profound although clearly people can be very damaged by a single act of abuse, *for example* people who have been raped.

Initial responses from informants confirmed what is evident in the literature; that sexual abuse and physical abuse are generally thought to be worse than the other types. Indeed one defined sexual abuse as a type of physical abuse. Thus the contact abuses are in the main thought to be more traumatic than non-contact. Moreover, as several informants believe that people who have learning disabilities do not experience emotional trauma as others do, it is little surprise that the physical abuse with its physical evidence is considered to be worse whilst the silence and absence of clearly demonstrable evidence of emotional suffering has less impact. Yet, if those who provided the evidence for the document entitled ‘Living in Fear’ (Mencap 1999) are representative of people with learning disabilities, many of the types of behaviours most offensive to them

resulted in no physical evidence. Thus, that which causes greater distress to the individual may be overlooked in risk assessment whilst attention is given to potential risks identified by staff according to their own values.

Intent to harm was associated with abuse. This finding is strengthened by the observation that the types of abuse that tended to be overlooked by informants, at least initially, included neglect and human rights infringements. Even after discussion some felt that neglect did not easily fall under the broad definition of abuse as it is often, they believed, the result of lack of knowledge or ignorance. Likewise lack of knowledge regarding the Human Rights Act 1998 and its application in care may result in infringements through ignorance and, since some of the informants admitted that they did not know their own rights, this is almost certainly the case. For instance denial of privileges was considered acceptable by some informants, even though the people on the receiving end of this decision were adults, and this was not seen as degrading in any way (Article 3).

Another example of lack of knowledge of this act related to Article 12 – Right to Marry which includes the right to marry and found a family. Although most of the informants supported the notion that people with learning disabilities should be entitled to have sexual relationships, several associated this with pleasure rather than procreation and in this latter regard several projected a likely negative impact to a child born to a person with learning disability. This therefore implies that preventing people with learning disabilities from having children through some means would be more desirable than risking the possibility of a poor upbringing or the possibility of inheriting poor genes. Additionally, some felt that the social impact of having a learning disabled parent or parents would be negative and should be avoided. This was not overtly acknowledged as sympathy with the eugenics movement although some argued that the rights of the (potential) offspring should be a consideration. Since there has been little if any research of the impact on the lives of people brought up in this type of situation, the views expressed on this subject were based more on perceived societal attitudes and personally held values. Thus the argument brought forward by Gates (1997a) regarding elimination of ‘bad’ genes was prevalent in this study even if not overtly acknowledged as that.

Unlike neglect and human rights infringement, bullying and harassment is done

with intent to harm however none of those carry the prefix/suffix 'abuse' and it was clear that initially they were not highlighted as such. Bullying and harassment however was seen differently from the other two. Although they were recognised for the unpleasantness associated with those behaviours they were seen as behaviour tolerated within the present culture that is difficult to change and in this regard and there a degree of acceptance that it will continue. Consequently discussions centred on risk management strategies that involved avoidance of situations where bullying and harassment might take place. Bullying and harassment were not considered to be as damaging as other types of abuse and further informants felt powerless to change societal views. Moreover abuse of this type may be difficult to prove due to lack of corroborating evidence therefore even if it is acknowledged it is felt that it would not result in action against the perpetrators.

Several respondents expressed views that one type of abuse seldom happens in isolation of others *for example* sexual abuse may also be accompanied by emotional abuse in situations where the victim is advised that they should not tell anyone as they may be moved away from home.

Financial abuse did not come readily to mind for most informants in this study and this may be linked to a perception that the damage from this type of abuse is less likely to impact on the individual who may not have the ability to manage his/her own affairs and may be less concerned with material effects. This perception may make it possible for people to abuse in this way in the belief that there is less harm. Furthermore if the individual whose money or possessions are being taken does not know it may never be detected.

Always when abuse takes place there is an immediate reactive response that, initially at least, may be based on the perceived impact of support staff based on their attitudes. However some people with learning disabilities may not be aware that they have been subject to behaviours that others may consider abusive. These findings, that indicate that people with learning disability are not always aware that they have been abused, indicate a need for great sensitivity in dealing with the aftermath should abuse be detected. Provided they have not felt violated in any way then the response to it should take account of this and be appropriate to the needs of the individual. If there is a criminal issue to be addressed then sensitive consideration of any individual involvement of the learning disabled

victim should be of paramount importance. Revelation of abuse and subsequent actions should not be more traumatic to the individual than the abusive behaviour.

To sum up on abuse, as reported in the previous chapter, one informant identified abuse as *any treatment that is unfair or any ill treatment towards a person which is unjustified* - that is no abuse is ever justified.

## 6.5 Power

Power, authority and control were all used by informants to describe the need to have the ability to manage challenging situations. This was stated by most to be necessary although in varying degrees depending on their philosophical positions or personal values. For instance those who expressed a view that people with learning disability have a right to self determination were more averse to notions of power and control. However, as has been reported in Chapter 5 in the most difficult situations 'last resort' options include the use of power. A sense of helplessness was conveyed in this regard. As informants explained, with changes in legislation and policy and the influence of normalisation theory, approaches such as use of seclusion or administration of medication were no longer considered acceptable. However they conveyed that there had not been a concomitant development of other approaches therefore they felt disempowered whilst also feeling they were unsupported by management in dealing with this challenge. As was reported, it was perceived that this was more in keeping with political correctness than addressing the challenges of the 'front-line' pressures faced by staff. This was not unique to any particular organisation. Moreover, if this view is widespread across care organisations then managers would be wise to address this lest staff feel so disempowered that they leave the service.

Whilst lack of power was felt by some informants, others felt the balance of power still is in favour of staff and that manipulation is used to deal with challenging behaviour, although most used less inflammatory language to describe the way in which they endeavoured to bring about change. That they need to have accepted strategies for management of challenging behaviour of the people they support was universally felt by informants and however unpalatable the notion this cannot be completely separated from balance of power. Nevertheless, it is acknowledged that people with learning disabilities are able to assert their views sometimes through noisy or aggressive behaviour albeit the



behaviour is sometimes counterproductive if support staff perceive this to be challenging behaviour.

As stated in the literature review (Chapter 2) the Mental Welfare Commission for Scotland in 2007 reticently acknowledged that in a few instances use of seclusion for some individuals may be appropriate. However in draft documents where they suggest detailed care planning and documentation in this regard they describe this as a paradox for the Commission since philosophically they do not agree with the use of it. In essence this is acknowledgement of the need for 'a last resort' which was claimed by several respondents in this study however in their guidance the MWC (2006 *pp* 2) remind the reader 'if people have a right to take risks how do care staff strike the right balance between freedom and risk of harm and when should they intervene?' In their guidance on the use of restraint the MWC (2006) recommend that a decision to use restraint should be clearly documented in the individual's care plan. Further they suggest that restraint should only be carried out by carers who have been adequately trained and this involves management and policy associated with restraint. In their guidance on use of seclusion however they (MWC 2007) state that seclusion should be a 'last resort' feature of the restraint policy however they make it clear that this should not be included in the individual care plan of any patient lest it be used too readily.

Although power or authority was felt necessary for staff to effect change, particularly in situations where the behaviour of persons with learning disabilities display behaviour that challenges them, power imbalance was also seen as a feature of all abusive situations. Thus care staff may not wish to express the need of power, control or authority lest they be perceived to be creating a situation ripe for abuse and this relates to the helplessness and powerlessness conveyed by some respondents.

It was evident that unqualified staff in particular had observed behaviour that they considered abusive yet they did not feel they could speak out against it. They cited greater knowledge of long serving staff or qualifications and education of colleagues as reasons why they might feel poorly placed to speak out. This highlights the likelihood that some people who are paid to support those with learning disability see their role more in relation to provision of care rather than an obligation to support them with all their needs including the need

of protection. Dominance and peer pressure are compelling behaviours and are very much concerned with issues of power. Influential power is not just the domain of qualified staff. Informal leaders who may be unqualified can also strongly influence care in either a positive or negative way. This is consistent with the findings where some informants felt that longer serving staff had greater influence whether or not they were qualified.

Nevertheless providing the training for staff in small domestic care settings has proved problematic as was reported in Chapter 5. Thus addressing those power issues through education will need to be considered creatively and addressed seriously by management if change in practice is to be enhanced.

Power is also abused to meet the needs of staff rather than those who they are paid to support and in this regard several informants spoke of the manner in which staff collude to that end. This in turn creates a greater chasm between staff and people with learning disabilities who they are employed to support since the former are able to choose what they will or will not do and the latter are relatively powerless to change that situation.

Abuse of power was also interpreted as power to do something and not so doing. A number of respondents provided examples ranging from carers influencing choice of music, television channel or activity when it would not be the choice of the learning disabled person(s) to deliberate neglect *that is* ignoring the individual or deliberately not providing care. Though the former may be attributed to ignorance, the latter most certainly is not.

## 6.6 Across the concepts

A resounding message permeating most of the interviews was the need for improved training/education regarding legislation policy and its application in practice. Those with less education felt the need of it. At the same time they felt that long service of some colleagues stood them in good stead for their support role. Thus experiential learning was also considered to be of value even though, like the inexperienced ones, long serving staff who support people in domestic settings where staff resources are limited may, like them, not have been released for training. Whilst there were expressed views that increased knowledge and experience equates to better care conversely there were also views that knowledge of long serving staff can be dated. This is an issue that requires to be

addressed as part of professional development planning that in turn is translated into strategic programmes for continuing professional planning.

Important though training and education are in changing behaviour the other resonant message from informants was the strong influence that family and personal values have on the way that they support people. Whilst it is essential therefore that training should be made available to all staff as new policy/legislation is implemented training should take account of the strong influence of personal values and attitudes and be reflective of it. This does not mean that the message is necessarily varied but, acknowledging that individual views may be in discord with the planned direction, allows for discussion regarding implementation in practice. Clegg (1999) writes of virtue ethics which is concerned with character, rather than rules or consequences, as the key element of ethical thinking. In support her argument for virtue ethics she suggests philosophers and clinicians consider that living truthfully requires us to embrace the uncertainties accompanying human action and having the strength to embrace uncertainty offers the best chance of avoiding error because ideas taken out of context have no intelligibility. Clegg cites Woody when she writes 'conflicting values between clients, carers and staff at different points within a medical system were also unravelled. All of these offer useful directions for ethical development among staff who provide intellectual disability services'. Considerations of ethical practice therefore must pay cognisance of the values of all concerned and where staff acknowledge that they are more influenced by personal and family values rather than on theory or policy and legislation is an ethical issue requiring of attention.

Most informants favoured facilitated discussion rather than reading documents and even though this may seem resource intensive initially the benefits of improved and more consistent practice might finally outweigh this cost.

Several informants were unclear regarding differences between legislation policy and theory. That theory underpins policy was not evident to all informants and in discussing policy and legislation several referred to the dominant theory of normalisation which they saw as influencing their practice. Yet it was evident in this study that normalisation theory for several informants was concerned with increased choice paying less cognisance to the other aspects of the theory. According to Walmsley (1997 *pp* 64) 'people with learning difficulties deserved

to have opportunities to enjoy normal patterns of life, the rhythms of the day and the seasons, the separation of work and play, an ordinary life, even within segregated services'. A number of informants referred to the (mis)application of normalisation theory just because people felt the need to be seen to be doing that which was viewed as politically correct. The negative impression that they do as they do to be politically correct conveys discord between what they feel/think and what they do. Therefore to ensure that the behaviour of employees is that which service providers desire, based on their philosophical position, the education regarding application of policy must be convincing and compelling.

The evident lack of clarity regarding legislation, policy and theory was evident across the care sector and not specific to any in particular raises to important issues:

- All sections of the care sector could benefit from shared knowledge and understanding of topics common to all
- Legislators and policy makers should be mindful of the practical implications of applying legislation and policy

According to Manthorpe *et al* (2004):

People with learning disabilities and their families are in contact, potentially, with a wide range of public and private bodies, not all of such contacts being with statutory health and social care services but including work, leisure, relationships and all spheres of ordinary life. UK policy, in respect of people with learning disabilities, increasingly relates to a spectrum of arenas, for example, education, housing and employment

Since people receive supports from different agencies there would be a strong argument for shared learning opportunities in order that those in receipt of services get a service that is seamless and based on shared understanding.

Inter-professional education and cross-professional development are terms used to describe shared learning opportunities (Editorial *in* Learning in Health & Social Care 2006). In this article, in which the content of the journal was being considered, the editor wrote 'we were all convinced that the professions in health and social care had much to learn from each other's approaches to and experiences of learning, as well as from shared learning among more than one profession'.

Where education relates to subjects that apply two more than one profession *such*

as interagency guidelines for adult protection, the benefits of inter-professional/interagency learning opportunities should be considered.

Application of legislation and policy in practice presents practical problems for care staff across the statutory and independent sectors. In this study there was some evidence that

- Finding time to become conversant with such documents was a challenge when considered against other priorities of providing care and support.
- staff find these documents difficult to understand and even ambiguous

As new legislation and policy is issued supporting abridged good practice guidelines should also be issued using plain English.

## 6.7 Comparison with other relevant research

Although there is more research into abuse of people with learning disability at the time of writing than there was during earlier stages of this study there is a paucity of studies that focus on staff attitudes in relation to abuse and/or vulnerability and all their related concepts such as risk. One such study however was reported in Surrey (Taylor and Dodd 2002) after commencement of this study. It was reviewed in Chapter 2. In comparison to this study where the focus related to attitudes of care staff supporting people with learning disabilities, Taylor and Dodd focussed on attitudes of staff supporting all vulnerable people and also included police attitudes, the results being presented by care category. As in this study, Taylor and Dodd reported that a high percentage (100%) of participants whose employment was supporting people with learning disabilities identified them as vulnerable. The same respondents did not see older adults, those with mental health problems, physical problems or sensory disabilities as vulnerable compared with those with learning disabilities.

There are many similarities between the results of the study conducted by Taylor and Dodd and those of this study. In particular respondents identified physical abuse, sexual abuse and psychological abuse more readily than they did financial abuse, human rights infringement and neglect. Like their study, the current study also showed that neglect is not spontaneously identified as abuse by many support staff. Reticence about reporting abuse in the absence of evidence was common to both Taylor and Dodd's study and this one. It is notable that bullying and harassment were not identified by any of the 150 respondents in the Surrey

study nor did the authors refer to it therefore it might be assumed that either these are not seen as abuse or are considered under a different definition such as psychological, verbal or emotional abuse.

Though Taylor & Dodd's study involved 150 respondents only 14 worked within learning disability services in Surrey compared with 20 in this study. The similarities between findings of the two studies that utilised similar semi-structured interview approaches are indicative that the findings of the current study are not peculiar to Grampian.

## 6.8 Reflections of the researcher

The purpose of this study was to conduct a detailed analysis of interpretations of the terms *vulnerability* and *abuse* within learning disability services and this has been achieved. However, on reflection, it became evident early in the data gathering stage that the volume of data generated on the two separate though related subjects would become so great as to make the data analysis challenging. This had not become apparent at the pilot stage when alterations to the interview schedule could have resulted in a narrowing of focus. With benefit of hindsight a more realistic study would have been one that explored views on vulnerability and risk or alternatively the subject of abuse. Nevertheless both subjects *that is* vulnerability and abuse, were explored and presented in the results in a manner that reflects the breadth of the study but focuses in depth on the main issues emerging from the data.

The study was carried out in accordance with the original interview schedule and explored fully with all informants consequently the study took much longer than originally anticipated. Not only was the project large on account of the focus on both vulnerability and abuse the volume of each successive interview increased compared with the earlier ones due to the enhanced ability of the researcher to draw out relevant information. As interviewer technique developed with the progress of the study participants seemed very keen to share their views on the subject and even when invited to terminate the interview at the end of the agreed hour no-one did. The longest interview took 90 minutes.

The qualitative approach adopted for the study enabled the researcher to explore with informants the subjects under investigation which was the aim of the study. Therefore on reflection this was the correct approach for the study.

### 6.8.1 *Personal values and their influence on this study*

It is recognised that the beliefs, values and attitudes of researchers and informants influence the outcome of the research. Although the outcome is influenced in this way so too is the research at every stage from the outset where the subject for investigation was chosen, through data collection, analysis and presentation of results. It is not possible for research to be value neutral. In this research something of my personal values were stated in Chapter 3. In analysing and presenting the case studies the personal values of informants are evident, though this is less clear in the analysis and presentation of emergent themes in Chapter 5 since the views of all informants are represented here. Nevertheless the values held by them are evident throughout this section.

### 6.8.2 *Study Design*

Initially it was felt that important that the sample should represent an even split across organisations, across genders and qualified/unqualified staff. However it became evident early in the data gathering and reaffirmed time and again as I progressed through the study informants were much more influenced by their beliefs, values and attitudes. Consequently although the sample had been a purposive one the criterion for the sample in the event were not strong influencing factors in the study.

The handling of data and presentation of results presented considerable challenge in this study due to the volume of information. To assist in this process, a matrix of themes (Appendix 6) was developed and this proved to be a successful approach to data management. The completed matrix facilitated the selection of case studies and themes.

### 6.8.3 *Contribution of this research*

At the outset of this study research relating to abuse and vulnerability had focussed mainly on sexual or physical abuse and important though research into those topics is little had been done to investigate the views of staff who support people with learning disabilities in all aspects of their lives including personal safety. Since commencement of the study however Taylor and Dodd (2002) reported their study in Surrey. Although their study was broader in focus *that is* all vulnerable adults across care groups, the focus of the study, like this one, was on staff attitudes. The findings of that study bore many similarities to the

findings of this one and this is an indicator that the findings in this study are not parochial to Grampian.

The findings of this study add to the knowledge base regarding staff understanding of the terms *vulnerability*, *abuse* and *risk*. This increased understanding should be utilised in the further development of adult protection policy. This new information should also be utilised in education of those who support or provide a service to people with learning disabilities. Education should take account of the influence of values and attitudes of support staff and learning opportunities should be created that facilitate them to explore the impact of those values and attitudes on the care and support they provide. Values based training should not be a separate entity – rather it should be integral to all training including adult protection.

Whilst interagency work on adult protection policy is developing the focus of that policy needs to shift from risk assessment and reacting to allegations of abuse toward safety planning that is reflective of aspirations of the individual with whom the plan is being developed. Safety planning would facilitate a shift away from risk aversion toward a more positive approach that supports people in a person centred way to enjoy life experiences even where there is some degree of risk. Further it may be less time consuming than a broad based risk assessment and plan for eventualities that will never happen if that is not within thoughts of the individual. It will also focus minds on supporting people rather than limiting their life experiences.

Interagency policy should be developed to reflect this shift in emphasis thus becoming more proactive and enabling rather than reactive and disabling.

#### 6.8.4 *Changing Culture*

Culture and behaviour within organisations is as important as the systems and processes that support performance management (Audit Commission – *accessed 5<sup>th</sup> February 2008*). In their document entitled ‘Change Here!: Managing to Improve Local Public Services’ the Audit Commission state:

Public services face huge challenges, if they are to deliver the improvements that users expect.

According to the Audit Commission:



Culture can be thought of as the sum total of the beliefs, values and behaviours of individuals within a given group, this organisation claims it is a means by which norms of acceptable behaviour are established.

However norms that are considered cultural are not always result in acceptable and in care services can result in bad culture hence the need to change through innovation. This requires people to think and act differently in new and innovative ways. In no aspect of care and support is this more evident than in adult protection for those who are vulnerable. Support staff must believe that vulnerable people have a right to feel and be safe whilst at the same time recognise the right of the individual to enjoy a fulfilling life. This requires them to think and act differently in the way in which they support people.

By considering that, like others, people with learning disabilities are not in a permanent state of vulnerability but instead experience periods of greater confidence, as proposed in Figure 6 of this chapter, when they feel empowered to try new experiences. At this point the individual can be supported to be as safe as possible with the support he/she needs to achieve the desired goal. Safety planning, detailed in Figure 7 provides a more supportive and less restrictive alternative to risk management planning.

## 7 CHAPTER 7 - CONCLUSIONS AND RECOMMENDATIONS

### 7.1 Conclusions

To conclude, this study has provided an exploration of the views of care staff working within services for people with learning disability about vulnerability and abuse. The information provided by informants raises important issues and as a result recommendations for organisations, for education and practice development and for further research are made.

#### 7.1.1 *Values and Beliefs*

- Despite being influenced strongly by personal values and beliefs, what was perceived to be politically correct also influenced care. The manner in which political correctness was discussed conveyed incongruity with personal values. Therein some informants felt that theory and policy was in conflict with their own beliefs. Consequently this affected the way they practiced.
- The practice of all informants was more influenced by personal beliefs and family and personal values than by any policy. This was related to all policy and not only that associated with adult protection. They do not associate knowledge of policy as fundamental to their practice believing instead that values based (*that is* their personal values) provide sound guiding principles for care. There is no reason to assume that people who support those with learning disabilities differ in this regard from those who support people associated with other care groups. Therefore the findings of this study may have wider applicability than learning disability care services.

#### 7.1.2 *Practice*

- The need of staff to have power, authority or control in situations that they consider challenging was very keenly felt by informants in this study. Their feelings of powerlessness were evident as approaches with which they were familiar were stripped away whilst it was felt nothing else was offered in its place.
- Reluctance to report colleagues for what is seen as softer abuse *such as* contemptuous or disrespectful practice leaves people, who should be protected

from this, exposed.

- Positive change to practice is best implemented where there is supporting education and guidance.

### 7.1.3 *Organisational issues*

- There is a need for honesty regarding whose or what vulnerability is being addressed in order that the potential risks may be addressed in the most appropriate way. The outcome of risk assessment is likely to be different if the perception is of organisational vulnerability rather than from a person centred perspective.
- Staff should feel supported as change is sought in the way in which they deal with behaviour that challenges. In particular when new ways of understanding and managing problem behaviour result in the withdrawal of other approaches with which they have been familiar *for example* seclusion
- Addressing the balance of power between staff and those they support is essential.
- Adult protection policy and risk assessment should not be employed as a mechanism to disable people from normal life experience. Rather policy should provide a framework for safety planning that is a person centred and enabling process.
- The lack of clarity surrounding interpretations of vulnerability presents difficulty for staff who provide support to those with learning disabilities. This lack of clarity is evident across legislation and policy that uses differing definitions despite all being developed with the same objective – to ensure adult protection. Consequently there is ambiguity for staff who must draw their own conclusions. Policy should clarify rather than confuse staff regarding definitions of vulnerability and abuse – they should be unambiguous if policy is to be applied properly.
- In agreement with the literature, this study found that sexual abuse and physical abuse were considered to be worse than other types of abuse.
- Policy needs to convey the message as concisely as possible as informants

conveyed their first priority is care and support of people with learning disabilities leaving little time for study of policies.

- Where there is a need for common understanding of policy across agencies *such as* health, social work, housing, police and education, all opportunities for shared or inter-professional learning should be considered.
- Clarifying the meaning of vulnerability and identifying risk will not necessarily eliminate all abuse. However better understanding of those concepts may in turn lead to better application of policy in practice leading to improved adult protection.
- Neglect is not seen by most informants as a type of abuse. This is consistent with the literature on the subject.
- Human Rights are seen as remote from care and the legislation is little understood. Therefore human rights infringements may be commonplace within care through ignorance.
- The lack of clarity regarding legislation and policy is not unique to that relevant only within learning disability but is a much broader issue.

#### *7.1.4 Adult Protection*

- The state of vulnerability is not a desirable one. Supporting people in a manner that improves their safety may also lead to increasing confidence and improved self esteem of people with learning disabilities.
- People with learning disabilities are not seen as equal citizens especially in relation to rights issues. In particular they are subject to some practices that if imposed on other adults might be considered degrading. There is also strength of feeling that whilst people who have learning disabilities should be able to have sexual relationships they should not have children.
- Adult Protection Policies often focus more on process to be followed after allegations of abuse are made rather than on safety planning. By the time this process has been reached the attempts to protect people and, as far as possible, ensure safety have failed. Consequently, any further actions are concerned with preventing reoccurrence, reporting and investigating claims and providing

support for the victim.

- People with learning disabilities are often victims of abuse but on occasions some are perpetrators of abuse. Protection and justice should be available to them as with other citizens. As with others in society, people with learning disabilities who are perpetrators of abuse must face the consequences of their actions though they may require support in this. People with learning disabilities are entitled to justice however those who offend should not escape justice on account of their learning disability.

### 7.1.5 *Education*

- Misapplication of theory in practice is more harmful than it is beneficial and the importance of sound education in this regard must never be overlooked.
- Education/training associated with new policy is seen as limited value by many informants as several indicated it is by self directed learning. Yet if employers expect staff to work within policy it is essential that staff become conversant with and understand it before they can apply it in practice. Employers must support staff in this endeavour by making the time available for staff to study either in a self directed way or where indicated in group settings.
- Several informants indicated that some care staff do not associate knowledge of policy as fundamental to their practice believing instead that their personal value base provides sound guiding principles for care.
- Whilst there were expressed views that increased knowledge and experience equates to better care conversely there were also views that knowledge of long serving staff can be dated. In order to ensure greater consistency all staff should access the same training regardless of length of service.
- Inter-professional education/cross-professional development should be considered where there is common core knowledge and where the benefits of shared understanding of different roles and responsibilities can enhance application in practice.

## 7.2. Recommendations

### 7.2.1 *Recommendations for organisation*

- Organisations need to balance corporate responsibilities with their duty to

support people in a manner that enhances their lives. In so doing they should make explicit that which is not negotiable *for example* the organisation could not support a risk plan where the anticipated risk is significant enough to cause serious harm.

- Clear definitions are required for the terms *vulnerability* and *risk*. In particular the definition of vulnerability should clarify whether that judgement is based on professional assessment or the individual expression of this by the person with learning disability.
- Emphasis should be given to neglect, human rights infringement and bullying and harassment in adult protection policy.
- Where staff develop risk management plans based on a conferred label of vulnerability their accountability for the decision should be explicit in the Adult Protection Policy particularly where they use their power/authority in a way that limits the individual with learning disability.
- The shift away from dated approaches to management of behaviour such as use of seclusion, use of restraint, denial of liberty etc is not felt to have been replaced by alternative methods therefore there is a feeling of powerlessness. Organisations should recognise that staff need to be advised, trained and supported to adopt new ways of working. They should be made aware of what they can do as well as that which is not acceptable.
- There is a strong sense of team loyalty within staff groups even when this is at the expense of protection of the people they are paid to support. Whistle blowing policy is not well known but, even where it is, there remains a reluctance to report a colleague. This cultural issue should be addressed in a proactive way if application of Adult Protection Policy is to be anything more than cosmetic.
- Policy development should acknowledge the influence of personal values and be explicit regarding the extent to which those values can influence application.
- Whilst the Grampian Interagency Guidance for Adult Protection does provide useful direction it does not sit alongside a Grampian-wide policy that addresses reasoned risk-taking that may on occasions result in a less favourable outcome. This is an area that requires attention if a balanced approach to risk is to be

embraced.

- Neglect, human rights infringement and bullying and harassment should be given a higher profile in staff training on abuse.
- In this study it was evident that care was more strongly influenced by personal values than by policy. How ethical practice is, if strongly influenced by individual values, must be a consideration for organisations. Variability of practice must also be a consideration since each care worker will hold different values. This is an issue that requires to be acknowledged and understood in any attempt to change practice that is strongly influenced by cultural issues and in particular issues relating to abuse.
- Managers of organisations should find ways of conveying the key themes in abridged versions whilst signposting to greater detail should this be deemed necessary.

### 7.2.2 *Recommendations for education and practice*

- Knowledge of adult protection policy requires to be addressed as part of professional development planning that in turn is translated into strategic programmes for continuing professional planning.
- The value of well informed experience is recognised and should be used along with other training approaches in the development of practice.
- Where practice development is based on legislative/policy change or new theory, sound education should be planned in advance of its introduction rather than following its introduction.
- There is a need to develop inter-professional and inter-agency learning within both education and within practice. This should involve all relevant disciplines dependent on topic. It should recognise that each discipline has a unique contribution to make.
- The strong influence of personal values should be recognised educationalists whose aim is to influence practice.
- In addition to facilitated workshops, education on person-centred planning approaches must contribute to preparation of staff to adjust the balance of power

*that is* toward the people they support

- It should be made explicit for staff what is, as well as what is not, acceptable in the management of behaviour that is challenging.

### 7.2.3 *Recommendations for further research*

- Personal and family values are very powerful influences as was evident in the findings of this study. There can be conflicts between personal values and policy in practice that should be acknowledged.

The impact of values on caring has been a neglected area of research and is worthy of further investigation.

- Within this study there was considerable lack of clarity on the part of informants between the concepts of risk and vulnerability. A more in depth study of those concepts than the current study could achieve could increase the knowledge base around the subjects.
- There is a need to explore power, control and authority in the management of behaviour that is seen as challenging
- Types of abuse that do not include the word abuse *for example* neglect, rights infringements, bullying and harassment receive less research attention than those that do for instance *sexual abuse* and *physical abuse*. Neglect, rights infringements and bullying and harassment should receive greater research attention.
- The different terminology relating to abuse associated with those who use services and lay terms for the same experiences of others perhaps confuses rather than enlightens staff.

Further study of this little addressed topic is warranted.

- Neglect is seen as a result of ignorance and thus is seen as unintentional harm if it is acknowledged. This is worthy of further investigation

### 7.2.4 *Recommendations for legislators and policy makers*

- For legislation and policy to be applied in practice it must be known and understood and it must be feasible to apply. Recognition of the time involved for care staff to keep their knowledge up to date is essential. Documents should be



written in plain English rather than legal language and abridged versions of the key points should be supported by good practice guidance that can be applied in all care settings.

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0 1 APR 2002

**MENTAL WELFARE COMMISSION FOR SCOTLAND**

Chairman: Ian J Miller OBE  
 Director: Dr J A T Dyer MB ChB FRCPsych



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Your ref:

Our ref: FS/EC  
*Please quote when replying*

Enquiries to: Dr Sinclair

Date: 19 April 2002

Dear Mr Stewart

I write following on from our previous correspondence and discussion about the retention of information when allegations, particularly of abuse, are made against a member of staff but not upheld. As I have said I did have further discussion regarding this with colleagues here at the Commission. It seems that it is in fact quite a common practice elsewhere in the country for some record of such events to be kept. As said before where an allegation is unproven or unfounded it is not the practice to keep this on an individual staff members record. However, matters are sometimes recorded either in an incidents log or as part of a register of complaints.

These issues were recently raised at a meeting of the Commission when the possibility of guidance to Health Care Trusts was considered. It was felt that in view of the wide ranging importance of these matters that the Scottish Executive should be approached regarding a need for issuing guidance on a national basis. The Commission has undertaken to write to the Scottish Executive about this. Hopefully this will ultimately result in the development of better practices to protect individual patients across the country.

Regards,

Yours sincerely

DR FLORA SINCLAIR  
 Medical Officer

MeJ/DrS/E0617042

## Introduction including context of the study

I am interested to know a little bit about your work history within care services.....how long within learning disability services, number of people using the service, your position within the organisation, etc.

In what way is reference made to people who live/work in services?

Were the adults within the service you worked in viewed in any way as childlike?

Are you aware of any policies about adult protection in Grampian?

What do you understand by the term 'at risk' – is it synonymous with vulnerability or is it different?

Do you believe that all care workers are familiar with policy relating to people who are vulnerable?

Do you believe that all care workers easily understand policy relating to people who are vulnerable?

How would you categorise abuse?

*Prompts* physical, psychological, emotional, verbal, financial, neglect, sexual, human rights bullying and harassment

Do you think some types of abuse are worse than others and if so which?

Can you think of any gender issues relating to abuse of vulnerable people?

Can I ask you to think about all the types of abuse to which you have referred? Which do you think is most damaging?

Do you think that people who have learning disabilities are likely to be of a similar view to you in respect of the last question?

Are any abhorrent?

Do you think that disability (the physical or mental attributes) is an integral part of the person or do you hold the view that people are only disabled because society, access etc is denied some people on account of cost and other pressures?

Care that is based on rights principles is of interest to me and in particular

The right to respect  
The right to liberty  
The right to found a family

In relation to right to respect I am interested to hear your views.

*Prompt* denial of privileges, age appropriateness, etc.

Prompt if an adult likes a cuddly toy should they be persuaded away from it because of the connotations of an adult using childlike things?

In relation to liberty what is your view of peoples' freedom to come and go as they

please?

*Prompt* seclusion, time out, locked accommodation?

How much do you believe decisions about locked doors is based on duty of care and how much on staffing requirements?

*Prompt* are the 2 linked?

Do you believe that all adults with a learning disability have a right to have a sexual relationship?

Do you feel that all people who have learning disabilities have a right to have children?

*Prompt* can you elaborate on your views?

*Further prompt* do you believe that women who have learning disabilities and in sexual relationships should be given contraceptive medication?

If a woman becomes pregnant should termination be considered?

*Prompt* should she be able to keep her child?

Have you any thoughts about how the child's life might be?

Do you think people who have learning disabilities have reason to feel vulnerable? If so whom might they fear?

How strongly does peer pressure between colleagues influence the way care is delivered?

Could you ever imagine a situation where there could be divided loyalty between clients and colleagues?

(If yes *prompt* the respondent to elaborate)

What are your thoughts about the use of sanctions in the management of behaviours that challenge services?

In your view, how accepting are people who have learning disabilities of discipline and control in their lives?

Have your views of vulnerability and/or abuse changed during your time within care services and if so could you elaborate on this?

How much are your views shaped by influences within your organisation and how much by your own values?

And finally, I am interested to hear your views on the power dynamics within services particularly between staff and clients where 10 is power completely with the client whilst 1 is completely powerless



Grampian Primary Care NHS Trust

Fiona Parley  
Nurse Manager  
Elmwood  
Royal Cornhill Hospital  
26 Cornhill Road  
Aberdeen  
AB25 2ZH

Recipient

Date  
Your Ref

Address

Our Ref      FP

Enquiries to Fiona Parley  
Extension    XXXXX  
Direct Line   XXXXX XXXXX  
Email: [XXXX@XXXXXXXXXX](mailto:XXXX@XXXXXXXXXX)

Dear Recipient

***Research – Abuse of adults who have learning disabilities and who live in residential services where the carers are paid workers***

I am a nurse who works within the Learning Disability Service of Grampian Primary Care NHS Trust. I have worked in the service for 20 years. In the past 4 years I have participated in the development of policy aimed at protecting vulnerable adults from abuse. I have however been concerned that policies relating to adult protection may be open to wide interpretation and that if that is so then those same policies may fail to meet the need.

It is in that connection that I write to you. I am presently undertaking a research degree through the Robert Gordon University that focuses on abuse of vulnerable adults and hope through that research to interview staff with experience within learning disabilities service across the care sector including the independent and voluntary sectors, local authority and health. The study is more concerned with staff perceptions of the terms abuse and vulnerability rather than on actual practice.

I would be most grateful if you would consider participating in this study. I attach a research subject information sheet and a consent form along with stamped addressed envelope for the return of the consent form.

Should you decide not to participate in the study no record of this initial contact will be kept and your decision will have no effect on your employment.

May I thank you for your time in considering this request and ask that you return the consent form regardless of whether or not you agree to participate.

Yours sincerely

Fiona Parley  
Nurse Manager

**INFORMATION SHEET**

*An exploration of the views of care staff in relation to abuse of vulnerable adults who have learning disabilities*

***Introduction***

Many people who have learning disabilities are vulnerable to abuse. However there is diversity in the interpretation of the terms vulnerability and abuse by both care staff and indeed in wider society. This research aims to explore this subject.

I would like to invite you to help in this study. I wish to explore the various interpretations of terms relating to vulnerability and abuse.

***What will I have to do if I take part?***

The study will involve 20 care staff working within learning disability services in both the public and the voluntary service. If you agree to take part, I would interview you on the aforementioned subject. The interview would not exceed one hour. It would be at a time and venue mutually agreed between us. Your interview would be recorded provided you agree to this otherwise I would keep hand written notes of the interview. Following transcription and reporting the findings of the study, the tapes and/or field notes would be destroyed. Data would be held on a secure computer until the findings were reported and thereafter destroyed. Data would be anonymised and you would not be recognisable in reports of the study

***What are the possible risks of taking part?***

The subject of abuse can be distressing. So too can the exploration of vulnerability. If through exploration of the subject you wished to access professional counselling I would assist you in your quest to find a suitable person.

If through the study you disclosed information relating to abuse in the care setting not previously shared with anyone I would support you to take further action if this was requested.

***Are there any possible benefits?***

You will not benefit personally from this study.

***Do I have to take part?***

No, taking part is voluntary. If you would prefer not to take part you do not have to give a reason. Your manager will not know if you decide not to participate in the study. You may withdraw from the study at any point and such a decision will not affect your employment.

***What do I do now?***

I will contact you in a few days. I can answer any questions and you can let me know if you are interested in taking part.

Thank you very much for considering taking part in our research.

**Fiona Parley, Nurse Manager  
Grampian Primary Care NHS Trust  
Telephone XXXXX XXXXXX**



## Appendix 5

Name of Volunteer:.....

Name of Study: Abuse of vulnerable adults who have learning disabilities

Principal Investigator: Fiona Parley

***The Grampian Research Ethics Committee of Grampian Health Board and the University of Aberdeen has approved this study.***

I have read the volunteer information sheet on the above study and have had the opportunity to discuss the details with the researcher, Fiona Parley and to ask questions.

I have agreed to take part in the study as it has been outlined to me, but I understand that I am completely free to withdraw from the study or any part of the study at any time I wish and that this will not affect my continuing medical treatment in any way.

I understand that the interviews are part of a research project designed to promote knowledge that it has been approved by the Grampian Research Ethics Committee and that it may be of no benefit to me personally. The Grampian Research Ethics Committee may wish to inspect the data collected at any time as part of its monitoring activities.

I hereby fully and freely consent/decline\* (Delete as appropriate) to participate in the study which has been fully explained to me.

Signature of Volunteer: .....

Date: .....

I confirm that I have explained to the volunteer named above, the nature and purpose of the tests to be undertaken.

Signature of Investigator: .....

Date : .....

	Interview Number																			
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
It is not clear if there is any difference between the terms vulnerable and 'at risk'	✓									✓	✓	✓	✓	✓	✓			✓	✓	
Dependence, powerlessness and vulnerability are linked										✓	✓	✓	✓	✓	✓				✓	✓
Risk and vulnerability are the same					✓			✓												
Risk greater than vulnerability										✓							✓		✓	✓
Risk taking is a feature of everyday life											✓		✓	✓		✓				
There is a balance between duty of care and risk assessment											✓	✓		✓						✓
Staff can protect people from risk but they cannot take away vulnerability.								✓	✓			✓		✓					✓	✓
A person may feel vulnerable but will only be 'at risk' where external factors come into play	✓			✓	✓						✓	✓	✓			✓	✓		✓	✓
Vulnerability is easily spotted though not easily defined				✓		✓		✓		✓		✓			✓	✓				
Vulnerability is exposed by lack of understanding and inability to communicate	✓	✓		✓				✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓
Vulnerability is not necessarily associated with care groups								✓		✓	✓		✓			✓	✓	✓		
The vulnerability label can be conferred on another	✓	✓	✓		✓	✓							✓					✓		
The reasons why abuse happens in large institutions is different from that in smaller domestic settings	✓																			
Staff need to take measures to protect people from risks			✓	✓		✓			✓		✓	✓		✓	✓			✓	✓	
Freedom and protection need to be balanced			✓																	
Staff feel the need of power/authority to manage difficult situations	✓	✓	✓	✓	✓				✓	✓			✓	✓	✓	✓	✓	✓	✓	✓
Manipulation is used to 'encourage' people to do as staff wish			✓				✓		✓	✓			✓							✓
Staff have more power than the people they support	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
In the absence of better strategies it is sometimes necessary to lock people into rooms to manage difficult situations	✓	✓	✓	✓	✓	✓					✓	✓	✓	✓		✓	✓	✓	✓	✓



	Interview Number																				
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	
The way in which staff work with people who have learning disability is based on mental age rather than actual age	✓	✓	✓							✓	✓		✓								
Labelling, stigma, marginalisation				✓																	
Changing labels won't change care																	✓		✓		✓
When staff use labelling practices it is done to make sense of their world for example nurses see patients														✓				✓	✓	✓	✓
Offensive labels are sometimes used by the public but sometimes also by staff		✓		✓		✓		✓	✓			✓	✓				✓	✓	✓	✓	✓
Labels are a feature of everyday life – people with learning disabilities also use labels for others			✓	✓															✓		
Staff are often educated about how to speak with people but they are seldom advised how to deal with offensive behaviour of others <i>ie</i> turn the other cheek or challenge						✓		✓	✓	✓			✓								
It is only negative labelling that leads to stigma			✓	✓		✓															
Political correctness gets in the way of doing the right thing and describing situations as they really are			✓								✓								✓		
People with learning disabilities are not viewed as equal citizens		✓	✓	✓					✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓
People who have learning disabilities don't always realise they have been abused								✓	✓	✓		✓					✓	✓	✓	✓	
Power is a feature of abuse					✓		✓						✓	✓				✓	✓	✓	✓
Abuse, particularly bullying and harassment, is seen as part of the lot of people with learning disabilities													✓						✓		
Some types of abuse are worse than others	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Personal experience influences the way that care staff view different types of abuse				✓	✓								✓							✓	✓
Neglect is not seen as abuse					✓	✓															

	Interview Number																			
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
Some types of abuse may be overlooked as they are viewed as less significant by support staff contrary to the views of the victims																				
Lack of education leaves staff/carers at risk of adopting an approach inconsistent with the principles of the organisation		✓			✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Deference is paid to long serving staff		✓				✓					✓									
Policies are difficult to understand and time is not available.		✓		✓	✓											✓	✓	✓		
Family and personal values are a greater influence than policy		✓	✓	✓	✓	✓	✓			✓	✓	✓	✓	✓			✓	✓	✓	
When normalisation is imposed on people we deny them the right to choose for themselves			✓					✓		✓	✓	✓	✓	✓			✓	✓	✓	✓
The Human Rights Act is viewed as remote from care.							✓					✓	✓		✓	✓	✓			✓
People should not have a right to children just because they want them.			✓	✓	✓		✓				✓								✓	
In their relationships with people with learning disabilities, care staff experience emotions that affect their interactions	✓	✓	✓												✓		✓			
Caution is necessary before making allegations of abuse		✓																		
New staff should be encouraged early on to speak out about practices they are uncomfortable about so that they can learn why certain practices happen		✓																		
It is not easy to speak out about negative practice			✓		✓	✓		✓		✓			✓	✓	✓					
Some colleagues collude in the use of unacceptable strategies to meet their own agendas			✓	✓		✓	✓					✓	✓	✓	✓		✓			
Care practice done with good intention or does not apparently offend the person on the receiving end is not abuse					✓					✓		✓	✓	✓	✓	✓				

Grampian Primary Care NHS Trust

Fiona Parley  
Nurse Manager  
Elmwood  
Royal Cornhill Hospital  
26 Cornhill Road  
Aberdeen  
AB25 2ZH

Participant  
Address

Date 1  
Your Ref  
Our Ref FP

Enquiries to Fiona Parley  
Extension XXXXX  
Direct Line XXXXX XXXXX  
Email: [xxxx@xxxxxxxxxxxx](mailto:xxxx@xxxxxxxxxxxx)

Dear Participant

### **Research – Abuse of Vulnerable Adults**

Many thanks for participating in my research. Please find enclosed the transcript of the interview. As I said your comments are in red and where I have added to the standard questions my comments are red highlighted with peach. Down the right hand column I have drawn themes from what I believed you were saying. If the themes are not a true representation please amend and return it to me and I can take account of your comments. Otherwise I would be grateful if you would sign the enclosed proforma and return it to me in the stamped addressed envelope.

Once again thank you for your support.

Yours sincerely

Fiona Parley  
Nurse Manager

**Research – Abuse of vulnerable adults**

Name/Signature .....

Date .....

I have read the transcript of my interview and the themes drawn from it.

\*It is a true reflection of the interview/I have amended the transcript to better reflect my comments (please delete as appropriate<sup>\*</sup>).

Date of Meeting: .....

GREC Number: .....

**GRAMPIAN RESEARCH ETHICS COMMITTEE****APPLICATION FORM**

**INSTRUCTIONS:** Please complete in type. Please place a circle around Yes/No options as appropriate. A version of this form is available on disc from the clerk to the GREC.

It is essential that this form is completed fully and sent with relevant enclosures. Please refer to the accompanying Guidance Notes when completing the form and complete the checklist before sending. Where a question is not applicable it is important to make this clear and not to leave it blank. **It is important that the language used in this application is clear and understandable to lay members.** All abbreviations should be explained.

When the project has implications for Grampian University Hospitals NHS Trust applicants should also **complete Part 3 of the form fully and send it to the R&D Office, Westburn House, Foresterhill, with a copy of Part 1 of the form and the protocol or grant application**, to enable the service support resource to be fully listed and allocated. When the project has implications for Grampian Primary Care NHS Trust a copy of Part 1 and 3 of the form along with the protocol or grant application should be sent to **R&D Office, Primary Care Resource Centre, Foresterhill Road, Aberdeen.**

**Applicant's Checklist for Ethics - to be sent to the GREC**

Please indicate if the following have been enclosed by crossing the Yes/No/Not applicable options.

	Yes	No	Not applicable
18 copies of Part 1 & 2 ( <b>not</b> part 3) of Application Form with 18 collated sets of the following where appropriate:	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Research subject consent form (or Annexe D)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Research subject information sheet	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Advertisement for research subjects	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
GP/consultant information sheet or letter	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Interview schedules for research subjects	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Letters of invitation to research subjects	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Questionnaire* Finalised/Not yet finalised	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Annexe A**	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Annexe B***	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Annexe C*****	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>One</b> copy of protocol	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>One</b> copy of researchers brochure or data sheet for all drugs	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>Applicant's Checklist for Research &amp; Development Office</b>			
	Yes	No	Not applicable
One Copy of Part 1 and 3 of Application Form	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
One Copy of Protocol or Grant Application	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

- \* *Please indicate if not yet finalised*
- \*\* *If the study involves the use of a new medicinal product or medical device, or the use of an existing product outside the terms of its product licence. Annexe A is attached to the Application Form and a copy of CTX/CTC/DDX where appropriate.*
- \*\*\* *If the study includes the use of ionising, radioactive substances or X-Rays. Annexe B is attached to the Application Form.*
- \*\*\*\* *Information concerning collaborative researchers should always be given where possible. Annexe C is attached to the Application Form.*

**FORM PART 1 - Copy (x18) to Ethics and Copy (x1) to R & D Office**

**SECTION 1.1**

**Details of Applicant(s)**

**1. Principal researcher**

Surname: **Parley** Forename: **Fiona** Title: **Mrs**  
 Present appointment of applicant: **Nurse Manager**  
 Number of Hours Per Week to be spent directly on this project : **12 - 15**  
 Qualifications: **RGN, RMN, RNLD, MSc (Nursing)**  
 Address: Home Address  
 Home Address  
 Home Address  
 Home Address  
 Tel: 01224 551566 Fax: E-Mail: **fiona.parley@gpct.grampian.scot.nhs.uk**  
 (day)

**4. Title of project**

**Working title** **Vulnerability and abuse: An exploration of views of care staff working with people who have learning disabilities**

Give one key word for each of the following:

Medical condition **Care group – Adults who have learning disabilities**  
 Field of study **Abuse of vulnerable adults**  
 Treatment **Not applicable to this study**

## FORM PART 1 - Copy (x18) to Ethics and Copy (x1) to R &amp; D Office

<b>Details of Applicants</b>
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**5. Proposed start date and duration**

Start Date : Immediate Duration (months) : 28

**6. What other centres are/do you intend to be involved in this project?**

*Please use the form attached at Annexe C. If five or more centres (covered by five or more Research Ethics Committees) are involved you MUST apply to the Multi Centre Ethics Committee using their form, see Annexe C for details.*

Not applicable

**7. Who is sponsoring / funding the study or to whom will an application be made?**

Contact Name: Fiona Parley (the researcher)

Organisation: As above

Address: As above

Tel: As above

Fax:

E-Mail: As above

Has funding been awarded? Yes  No

If commercially funded is the project/ or will it be managed by MARU? Yes  No

**The project is self funded by the researcher who is a research student at RGU for submission for PhD**

**8. (a) Indicate the location of the project** ie at which department will the patients/volunteers be presenting?

Within learning disability services in health, local authority, voluntary and independent care sector

**(b) List other departments/laboratories (eg Pharmacy, Pathology, Radiology, Medical Records) which are involved in additional work or time**

Not applicable

**(c) Has permission been obtained from these departments/laboratories?**

Yes  No

*If yes, name the person who gave permission.*

Not applicable

**FORM PART 1 - Copy (x18) to Ethics and Copy (x1) to R & D Office**

*This section must be completed. A copy of the protocol should be enclosed with the application form, but it is not sufficient to complete questions by referring to the protocol. It is important that the language used is clear and understandable to lay members. All abbreviations should be explained.*

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The work plan for the study is attached

**9. Aims and objectives of project** (maximum 250 words)

Aim

To conduct a detailed concept analysis of vulnerability and its relationship to abuse within learning disability services

Objectives

- Carry out a review of the literature relating to abuse of vulnerable people and in particular adults who have learning disabilities
- Ascertain the views of staff relating to vulnerability and abuse through use of semi-structured interviews
- Clarify the range of meanings of the terminology used in relation to vulnerability and abuse
- Establish whether power within the relationship between research subjects and people who have learning disabilities may have influenced care

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**10. Scientific background of study** Please use language that is understandable to non specialists. (maximum 500 words)

**The researcher aims to explore care staff views of vulnerability and its relationship to abuse within learning disability services. This will be done through the use of semi-structured interview. It is hoped that 20 people will be prepared to participate in the study. Detailed analysis of the data will be carried out to establish whether or not there is commonality in the interpretation of those terms.**

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**11. Brief outline of project** Please use language that is understandable to non specialists (maximum 250 words).

This study, which is part of a PhD research programme through RGU, is concerned with adult protection for those who have learning disabilities. In recent years policy has been developed for the protection of vulnerable people. Yet each policy uses its own language and is based on particular service views of vulnerability and abuse hence it may not adequately protect those it seeks to or perhaps overprotects where the person deemed vulnerable has no say in the matter.

The researcher has worked in the NHS for 27 years and during that time has seen many practices that within the present day culture would be deemed abusive. The researcher's



more recent experience of the topic has been from a management perspective investigating allegations of abuse. This was a traumatic experience for all concerned including service users who had made the allegations and their peers, staff, management and people against whom allegations had been made. Much has been learned from the experience but there is a dearth of relevant research on this topic on which to base best practice. In the experience of the researcher, in many cases of alleged abuse student nurses have been the people who have made the disclosures normally after their placement has ended. This may be an indication that they would have been afraid to report their concerns during placement for fear of reprisals. Although in the United Kingdom we have a Public Interest Disclosure Act (Department of Trade and Industry 1998) either people do not know of it or they do not have any faith in it.

Although there is a plethora of research on elder abuse and on child abuse most of the research in learning disability has as a focus sexual abuse with little attention being given to the many other ways in which people are abused. It is difficult to attach a particular value or score to the different types of abuse since all abuse is harmful. Systematic bullying can be more damaging to people than a single act of frustration that is manifest in a physical assault *such as* a slap.

In March 2000 the Department of Health (DOH 2000) launched its guidance entitled 'No secrets: Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse', in which they proposed the development and implementation of multi-agency policies and procedures for protecting vulnerable adults.

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**12. Study design - indicate study type - you may tick more than one box, if other please specify**

- |  |                                     |
|--|-------------------------------------|
| Re-analysis of original data           | <input type="checkbox"/>            |
| Randomised Controlled Trial            | <input type="checkbox"/>            |
| Laboratory Study                       | <input type="checkbox"/>            |
| Controlled Trial without randomisation | <input type="checkbox"/>            |
| Case note review                       | <input type="checkbox"/>            |
| Before-After study                     | <input type="checkbox"/>            |
| Database analysis                      | <input type="checkbox"/>            |
| Case-Control study                     | <input type="checkbox"/>            |
| Questionnaires                         | <input type="checkbox"/>            |
| Cohort observation                     | <input type="checkbox"/>            |
| Participant observation                | <input type="checkbox"/>            |
| X-sectional study                      | <input type="checkbox"/>            |
| Interviews                             | <input checked="" type="checkbox"/> |
| Epidemiology                           | <input type="checkbox"/>            |
| Other                                  | <input type="checkbox"/>            |
| Please Specify _____                   |                                     |

**13. Please list those procedures in the study to which subjects will be exposed indicating**

- i) procedures which are part of standard care

*Not applicable*

- ii) procedures that will be additional to standard care (eg taking more samples than

would otherwise be necessary)

*Not applicable*

iii) where treatment is withheld as a result of taking part in the project.

*Not applicable*

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#### **14. Size of the study**

##### **i) Patients/volunteers**

(a) How many subjects will be recruited?

20

(b) How will they be recruited?

It is hoped that participants can be recruited across the organisations of the care sector including the statutory sector; *Health, and Local Authority*, and Independent. Sector; *private and voluntary*. Managers of the organisations would be approached regarding the study and if agreeing to participation they will be asked to identify 5 staff.

(c) What selection/inclusion criteria will be used?

Stratified Random Sample will be used. If all agencies approached agree participation this would provide four agencies with five participants from each. Within each organisation a gender mix representative of the agency would be sought with a mix of qualified and unqualified, experienced and more recent recruits.

(d) What exclusion criteria will be used?

No exclusion criteria have been identified

##### **) Controls (please state if not applicable)**

(a) How many controls will be recruited?

Not applicable

(b) How will they be recruited?

Not applicable

(c) What selection/inclusion criteria will be used?

Not applicable

(d) What exclusion criteria will be used?

Not applicable

##### **iii) What is the primary end point?**

The end point will be the production of a thesis in which the findings of the study will be reported. The study should lead to an increase in the body of knowledge

around the subject of abuse of adults who have learning disabilities.

**iv) How was the size of the study determined?** (not applicable for pilot studies)

Since the care sector involves 4 types of agencies (health, local authority, voluntary and independent care sectors) it was felt that all should have the opportunity to Participate. As the study is a qualitative one it was felt that five staff members from each would provide a suitable representation of each type of organisation

**v) If a quantitative study, what is the statistical power?** (not applicable for pilot studies)

Not applicable

**15. Please advise the number of other trials/studies in which the local researcher**

a) is currently involved None

b) has been involved in the last six months One pilot study for University of Glamorgan

**16. Will researchers be paid for taking part in the study?** Yes  No

Will BMA guidelines (Manual II.47 - see Guidelines) be followed? If not, why not?  
Not applicable

If commercially sponsored, state amount received (in total / per patient).

SECTION 2.2	Ethics	Consent
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**17. Is written consent to be obtained?** Yes  No

If yes, please attach a copy of the consent form (*Annexe D* - the model Consent Form or the one you plan to use).

If no written consent is to be obtained, please justify.

**18. How long will the subject have to decide whether to take part in the study?**

The consent letters will be sent out and a follow-up telephone call made one week later.  
If fewer than 24 hours please justify.

**19. Will the subject be given a written information sheet or letter?** Yes  No

Please see Guidelines

If yes, please attach a copy to this application form.

If no, please justify.

**20. Have any special arrangements been made for subjects for whom English is not a first language?**

Yes   
 No   
 N/A

If yes, give details.

If no, please justify. The researcher anticipates that the nature of the work within learning disability services in Grampian is such that, even if not the first language, all employees would need to be conversant with English.

**21. Will any of the subjects or controls be from one of the following vulnerable groups?**

- Children under 16  
 People with learning difficulties  
 Other vulnerable groups eg mental illness, dementia  
 Unconscious or severely ill

Please specify and justify. Not applicable

**What special arrangements have been made to deal with the issues of consent for the subjects above? Please see Guidelines.**

**22. i) Are any of the subjects likely to be involved in existing research or have been involved in any recent research in the last six months?**

Yes  No

If yes, please justify their use in this project

**ii) Will any of the subjects involved be in a dependent relationship with the researcher?**

Yes   
 No

If yes, please justify their use in this project

As the most senior member of nursing staff within learning disability health services, the researcher has management responsibility for the entire nursing group therefore it could be argued that the subjects selected from health may feel dependence on her. It is not however their practice on which the researcher will focus. Rather, the focus will be on the views of the subjects regarding interpretation of specific terminology relating to abuse and vulnerability and in that respect subjects are entitled to hold the views they do.

**iii) Will there be payment to research subjects of any sort? Yes  No**

If so, how much per subject and for what?

#### Details of Interventions

**23. Does the study involve the use of a new medicinal product or medical device, or**

**the use of an existing product outside the terms of its product licence?** Please see Guidelines. Yes  No

*If yes, please complete Annexe A of the Application Form.*

**24. Will any ionising or radioactive substances or X-Rays be administered?**

Yes  No

Please ensure information in Question 14 includes exclusion criteria with regard to ionising radiation if appropriate.

*If yes, please complete Annexe B.*

Risks and ethical problems

**25. Are there any potential hazards?**

Yes  No

If yes, please give details, and give the likelihood and details of precautions taken to meet them, and arrangements to deal with adverse events.

**26. Is this study likely to cause discomfort or distress?**

Yes  No

If yes, please give details.

The researcher will have no prior knowledge of any abusive situation previously experienced by any subject. Should such abuse be disclosed the researcher would support the individual to seek the support that best suits them should they wish to do so *for example* a counsellor may be necessary and depending on the nature of the disclosure the appropriate organisation could be approached.

Subjects may take the opportunity to highlight abuse within their organisation. It will be made clear to subjects at an early stage that if disclosures made seem to be of a criminal nature that the information will be provided to the appropriate authority.

**27. Are there any particular ethical problems or considerations that you consider to be important or difficult with the proposed study?**

Yes  No

If yes, please give details.

**28. Will information be given to the patient's General Practitioner?** Yes  No

Please note: permission should always be sought from research subjects before doing this.

If yes, please enclose an information sheet for the GP.

If no, please justify.

**If the study is on hospital patients, will consent of all consultants whose patients are involved in this research be sought?** Yes  No

If no, please justify.

Not applicable

Indemnity and confidentiality
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*Product liability and consumer protection legislation make the supplier and producer (manufacturer) or any person changing the nature of a substance, eg by dilution, strictly liable for any harm resulting from a consumer's (subject or patient) use of a product.*

29. Have arrangements been made to provide indemnification and/or compensation on behalf of a subject for:

a) pharmaceutical company sponsored research? Yes  No

b) healthy volunteers? Yes  No

Not applicable

For all research a medical indemnity form requires to be completed on gaining ethical approval. This form will be provided by the GREC office along with the approval letter.

**30. In cases of equipment or medical devices, have appropriate arrangements been made with the manufacturer to provide indemnification?**

(Please indicate N/A if not applicable)

Yes  No  N/A

**31. i) Will the study data be retrieved from computer?** Yes  No

ii) Will the study data be held on a computer? Yes  No

iii) If yes, will the Data Protection Act (1998) be followed? Yes  No

**32. Will the study include the use of any of the following?**

Audio/video recording Yes  No

Observation of patients Yes  No

If yes to either:

i) **How are confidentiality and anonymity to be ensured?**

Recordings will be kept in a secure office in the researchers home and destroyed after the tapes have been transcribed and the findings reported.

**ii) What arrangements have been made to obtain consent for these procedures?**

Subjects will be given the opportunity to decline to be recorded in which case the researcher will keep field notes. Subjects who agree to recording will be advised of the disposal procedure.

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**FORM PART 2 - Copy (x18) to Ethics**

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**Indemnity and confidentiality**

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**33. Will the study involve the use of patient records?** Yes  No

If yes,

**i) Will the records be examined by researchers outside the employment of the NHS?**

Yes  No

If yes, please see Guidelines.

Not applicable

**ii) What steps will be taken to safeguard confidentiality of personal records?**

Not Applicable

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**34. What steps will be taken to safeguard specimens?**

Not applicable

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**35. Will the study involve DNA testing of samples from the subjects?** Yes  No

If yes,

**i) What arrangements have been made to obtain consent for this investigation?**

**ii) How are confidentiality and anonymity to be ensured?**

**ii) Genetic testing may generate information important to the subject's family as well as to the subject.**

**If the test results are not anonymous, what arrangements have been made to deal with these issues?**

**iv) Will there be any subsequent commercial use of the samples (eg for the production of gene lines)?** Yes  No

If yes, please give details

Declaration
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PLEASE ENSURE THAT YOU COMPLETE THE CHECKLIST ON THE FRONT COVER OF THE APPLICATION FORM AND ENCLOSE ALL RELEVANT ADDITIONAL DOCUMENTS.

**DECLARATION**

The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.

I understand it is my responsibility to obtain management approval where appropriate from the relevant NHS body before the project takes place.

I agree to supply interim and final reports, and to advise my sponsor, and the GREC from which approval was granted for this proposal of any adverse or unexpected events that may occur during this project.

Signature of Principal Researcher: ..... Date: .....

Signature of Head of Department: ..... Date: .....

**37. Please indicate which GUHT/GPCT specialties the proposed research/outcomes project relates to - you may tick more than one box**

Accident & Emergency	<input type="checkbox"/>	General Medicine	<input type="checkbox"/>
Oncology	<input type="checkbox"/>	Adult Mental Health	<input type="checkbox"/>
General Surgery	<input type="checkbox"/>	Ophthalmology	<input type="checkbox"/>
Anaesthetics & ITU	<input type="checkbox"/>	Genetics	<input type="checkbox"/>
Oral Medicine	<input type="checkbox"/>	Audiological Medicine	<input type="checkbox"/>
Care of the Elderly	<input type="checkbox"/>	Orthopaedics	<input type="checkbox"/>
Behavioural Oncology	<input type="checkbox"/>	GUM	<input type="checkbox"/>
PAM	<input type="checkbox"/>	Cardiology	<input type="checkbox"/>
Histopathology	<input type="checkbox"/>	Palliative Care	<input type="checkbox"/>
Cardiothoracic Surgery	<input type="checkbox"/>	Immunology	<input type="checkbox"/>
Pharmacy	<input type="checkbox"/>	Child Health	<input type="checkbox"/>
Infectious Disease	<input type="checkbox"/>	Physical Sciences	<input type="checkbox"/>
Clinical Biochemistry	<input type="checkbox"/>	Laboratory Haematology	<input type="checkbox"/>
Plastic Surgery	<input type="checkbox"/>	Clinical Haematology	<input type="checkbox"/>
Learning Disabilities	<input checked="" type="checkbox"/>	Primary Care	<input type="checkbox"/>
Clinical Pharmacology	<input type="checkbox"/>	Microbiology	<input type="checkbox"/>
Radiology	<input type="checkbox"/>	Community Nursing	<input type="checkbox"/>
Neonatology	<input type="checkbox"/>	Rehabilitation	<input type="checkbox"/>
Dentistry	<input type="checkbox"/>	Nephrology	<input type="checkbox"/>
Renal Medicine	<input type="checkbox"/>	Dermatology	<input type="checkbox"/>
Neurology	<input type="checkbox"/>	Respiratory Medicine	<input type="checkbox"/>
Diabetes / Metabolic Disease	<input type="checkbox"/>	Neurosurgery	<input type="checkbox"/>
Rheumatology	<input type="checkbox"/>	Elderly Mental Health	<input type="checkbox"/>
Nuclear Medicine	<input type="checkbox"/>	Stroke Medicine	<input type="checkbox"/>
Endocrinology	<input type="checkbox"/>	Nursing Research	<input type="checkbox"/>
Substance Misuse	<input type="checkbox"/>	ENT	<input type="checkbox"/>
Nutrition	<input type="checkbox"/>	Urology	<input type="checkbox"/>
Gastroenterology	<input type="checkbox"/>	Obstetrics & Gynaecology	<input type="checkbox"/>
Vascular	<input type="checkbox"/>		

**38. If this project concerns CLINICAL GUIDELINES or OUTCOME OF**



**CLINICAL INTERVENTIONS please indicate type of project:**

- |  |                          |
|--|--------------------------|
| Measurement of clinical outcome within clinical service            | <input type="checkbox"/> |
| Development of system to measure clinical outcome within a service | <input type="checkbox"/> |
| Development of new clinical guidelines                             | <input type="checkbox"/> |
| Other type of outcome/healthcare evaluation                        | <input type="checkbox"/> |

**Details of Project**

*The following 4 sections request information on research themes which are specific to each Trust and University. The information will be used by each organisation and therefore there is some apparent duplication. Please **only** complete the section(s) that are relevant to this project.*

**39. Please indicate the relevant Grampian University Hospitals NHS Trust research theme****Disease and the Environment****Influencing Change in Practice**

- |   |                          |
|---|--------------------------|
| Epidemiology of Common Diseases             | <input type="checkbox"/> |
| Clinical Outcome Measures                   | <input type="checkbox"/> |
| Gene/Environment Interactions               | <input type="checkbox"/> |
| Development of Quality of Life Measures     | <input type="checkbox"/> |
| Nutrition and Disease                       | <input type="checkbox"/> |
| Developing ways to Change Clinical Practice | <input type="checkbox"/> |

**Evaluation of Therapy Management****Pathophysiology of Diseases**

- |   |                          |
|---|--------------------------|
| Controlled Clinical Trials of Treatment | <input type="checkbox"/> |
| Analyses of Disease Processes           | <input type="checkbox"/> |
| Economic Evaluation of Treatment        | <input type="checkbox"/> |
| Genetic Basis of Disease                | <input type="checkbox"/> |
| Evaluation of New Technologies          | <input type="checkbox"/> |
| Imaging Disease Processes               | <input type="checkbox"/> |
| Systematic Reviews of Management        | <input type="checkbox"/> |
| Microbiology                            | <input type="checkbox"/> |

**40. Please indicate the Grampian Primary Care NHS Trust research theme if appropriate**

- |                              |                                     |
|------------------------------|-------------------------------------|
| Care of the elderly & ageing | <input type="checkbox"/>            |
| Radiology & imaging          | <input type="checkbox"/>            |
| Child health                 | <input type="checkbox"/>            |
| Rehabilitation               | <input type="checkbox"/>            |
| Mental health                | <input checked="" type="checkbox"/> |
| Reproductive health          | <input type="checkbox"/>            |
| Primary care                 | <input type="checkbox"/>            |

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**41. Please indicate the Aberdeen University research theme if appropriate**
**Category 1**

Molecular Medicine	<input type="checkbox"/>
Bio-Physical Sciences & Bio-Engineering	<input type="checkbox"/>
Health Services Research	<input type="checkbox"/>
Molecular & Cell Pathology	<input type="checkbox"/>
Neuroscience and Mental Health	<input type="checkbox"/>
Microbiology	<input type="checkbox"/>

**Category 2**

Cardiovascular Disease	<input type="checkbox"/>
Reproductive Medicine	<input type="checkbox"/>
Nutrition	<input type="checkbox"/>
Cell Physiology & Pharmacology	<input type="checkbox"/>
Safety & Health	<input type="checkbox"/>
Sports Science & Medicine	<input type="checkbox"/>

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**42. Please indicate The Robert Gordon University research theme if appropriate**

Care of the elderly	<input type="checkbox"/>
Occupational therapy	<input type="checkbox"/>
Child health & disability	<input type="checkbox"/>
Patient consultation & involvement	<input type="checkbox"/>
Comparative health and social care	<input type="checkbox"/>
Pharmacy	<input type="checkbox"/>
Diet & lifestyle including quality of life	<input type="checkbox"/>
Physiotherapy	<input type="checkbox"/>
Evaluation of services and practice development	<input checked="" type="checkbox"/>
Primary & community care	<input type="checkbox"/>
Evidence-based practice	<input type="checkbox"/>
Radiography	<input type="checkbox"/>
Nutrition science	<input type="checkbox"/>
Rehabilitation & neurological disorders	<input type="checkbox"/>
Nursing and Midwifery	<input type="checkbox"/>
The art of nursing	<input type="checkbox"/>
Occupational health	<input type="checkbox"/>

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Project Funding
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**43. Is GUHT/AU/GHB/GPCT/RGU the lead institution for the project?**

 Yes  No 

If No, please identify lead institution below

**Lead institution:**

The Robert Gordon University is overseeing the research which will be submitted for a research degree at PhD level.

- 44. Will this project lead to a further qualification?** Yes  No   
If Yes, please name the person, their department and the qualification to be attained.

**Name and Department:**

Fiona Parley – Nursing (Learning Disability) employed within Grampian Care NHS Trust  
Robert Gordon University

**Qualification:**

PhD

- 45.a** Is the project being submitted for (or obtained) external funding? Yes  No

If Yes, please indicate the funding body and contact name if not already stated in Section 1.1, question 7

The project is being carried out for submission for a research degree and is being funded personally by the researcher. Approval for paid time for interviews has been agreed with GPCT

**b Please summarise the funding requested (or already in place)**

Part of the R&D funding arrangement with the Chief Scientist Office requires the assessment of NHS service support costs. It is important that all additional costs be identified so that they can be included in this assessment.

- 46. Will the proposed project involve subject recruitment within an NHS department?**

Yes  No

*If Yes,* It is hoped that 5 subjects will be recruited from health

- i) Please estimate the time taken per subject for recruitment into the study**

One person within each of the 4 provider agencies (possibly a payroll officer) will be required to identify 5 subjects who meet the inclusion criteria. This should take at maximum 1 hour.

Maximum 1 hour for each interview

- ii) Where will this take place (if different to the department where subjects will be presenting as stated in Section 1.1, question 8a)?**

At a venue of the subjects choosing

- 47. If the project requires procedures, data collection and/or completion of questionnaires that will be additional to standard care (as indicated in Section 1.2, question 13) at, for example, a clinic/ward/theatre or community/domicillary visit**

i) **Does this involve an additional visit?** Yes  No

If Yes, please state where, the length of time of the visit and number of extra visits per patient including follow-up visits.

**Not applicable** – subjects are employees

ii) **Does this involve an increase in time to a standard visit?** Yes  No

If Yes, please state where and the additional length of time.

**Not applicable**

iii) **Does this involve a decrease in visits?** Yes  No

If Yes, please give details.

**Not applicable**

---

**48.a Please list all NHS staff working on the project IN ADDITION to the co-applicants, their time on the project and whether this has been costed as part of a grant application.**

Not applicable

<b>Position from Grant (Yes/No)</b>	<b>Number of Staff</b>	<b>s/Week on Project</b>	<b>Funded</b>
-------------------------------------	------------------------	--------------------------	---------------

Junior Clinical  
Non-Clinical  
Nurse  
PAMs  
Secretary  
Technician  
Other Staff  
(please give details)

Other than respondents previously mentioned no-one else will be involved

**b. Please state if any of the above staff or co-applicants will be an additional appointment required for this project.** If Yes, please give details.

Not applicable

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**49. Are there additional NHS service costs incurred by the project which are not covered in the funding request summary (eg consumables, equipment) and have not already been detailed above?**

If yes, please state below Yes  No

Not applicable

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**50. Will the proposed project entail any requirement for additional accommodation or alterations to existing accommodation?** Yes  No

If Yes, please supply supporting information

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**51. Does this research require the use of drugs?** Yes  No

- 52. If successful how will this research change current clinical practice?**  
*Please include full details*

Change	Yes	No	Number Per Patient	Comments
Increase in Outpatient Clinic Activity	<input type="checkbox"/>	<input type="checkbox"/>		
Decrease in Outpatient Clinic Activity	<input type="checkbox"/>	<input type="checkbox"/>		
Increase in Inpatient Stay	<input type="checkbox"/>	<input type="checkbox"/>		
Decrease in Inpatient Stay	<input type="checkbox"/>	<input type="checkbox"/>		
Increase in Domicillary Visits	<input type="checkbox"/>	<input type="checkbox"/>		
Decrease in Domicillary Visits	<input type="checkbox"/>	<input type="checkbox"/>		
Increase in Procedures	<input checked="" type="checkbox"/>	<input type="checkbox"/>		Possible improved procedures
Decrease in Procedures	<input type="checkbox"/>	<input type="checkbox"/>		

*Please provide any additional information you consider relevant to the changes in clinical practice, eg changes in patient flow.*

If the research leads to better understanding and shared acceptance of the terminology in relation to vulnerability and abuse of the client group procedures for adult protection could be enhanced.

- 
- 53. The following CHECKLIST must be completed by the principal investigator's HEAD OF SERVICE / UNIT:**

1. Is there a hypothesis?	Yes <input type="checkbox"/>	No <input checked="" type="checkbox"/>
2. Is there an appropriate literature review?	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>
3. Is the research protocol clear?	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>
4. Is the clinical/biological significance of the study explained?	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>
5. Are study numbers discussed and justified?	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>
6. Is statistical analysis required?	Yes <input type="checkbox"/>	No <input checked="" type="checkbox"/>
<b>If yes to (6), Is there a discussion of statistical methods?</b>	Yes <input type="checkbox"/>	No <input type="checkbox"/>

**If the project employs qualitative research methodology, in addition please complete the following:**

1. Is reference made to accepted procedures for analysis?	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>
2. Are measures being proposed to test the validity of the findings?	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>
3. Are there any contingency plans in case of poor response/sample size?	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>

Approved by Head of Service/ Unit Signature	Name in block capitals	Date

**DECLARATION:** I have read and followed the procedure for project registration as detailed in the *Research Process and Research Grants and Contracts Procedure Policy*. **I will inform the R&D Office as soon as I hear the outcome of any application for funding for the proposed project and/or there are any significant changes to this proposal.** I am aware that acceptance of this grant, if it is offered, will not constitute any undertaking on the part of the Hospital or University to assume financial responsibility for the project after expiry of the period of the grant now requested.

	Signature	Name in block capitals	Date
<b>Principal Investigator</b>			
<b>Approved by Clinical Director (if clinical project)</b>			
<b>Approved by R&amp;D Director</b>			

**Contact telephone/extension number of PRINCIPAL INVESTIGATOR:**

**Please supply any SUPPORTING INFORMATION on an additional sheet**

.

31<sup>st</sup> October 2003

Mrs Kellie McLeod  
Grampian Research Ethics Committee Manager  
NHS Grampian  
Summerfield House  
2 Eday Road  
Aberdeen  
AB15 6RE

Dear Mrs McLeod

An exploration of views of care staff in relation to abuse of adults who have learning disabilities – Project Number 03/0230

Thank you for your letter confirming ethical approval for the above study subject to specified amendments.

On the issue of peer review the work to date has been shared with colleagues within health and to a lesser extent with colleagues in social work. The Director of Nursing reviewed the entire study before completing Part 3 of the GREC form. The learning disability nurse advisor in the Royal College of Nursing has informally reviewed the early work of this study. A supervisory team from The Robert Gordon University is guiding the research. As part of the research process the research is reviewed by two independent referees both of whom work within Social Studies

On reviewing my GREC application I realise the sampling method may have been made clearer. It is not the intention that a manager will select the subjects by any means other than a random method such as payroll return. Subjects who are invited to participate will be free to decline and their employment will not be affected by such a decision and this will be done by letter (see attached letter, information sheet and consent form). There is no need for nominated subjects to have any contact with the researcher and there will be no follow-up if that is their wish. I believe the nature of the study would be affected by inviting volunteers as it is likely that only those who believed their value base on this issue to be sound would be likely to volunteer. I have amended the letter taking account of your comments.

All data will be kept in a secure filing cabinet to which only the researcher has access

Patient information sheet

I did not receive a model patient information sheet but have submitted an amended one (attached) which is based on the comments in your letter. No patients will be involved in the study and direct patient care will not be affected by the study.

I trust this addresses the issues raised in your letter.

Yours sincerely

Fiona Parley

Fiona Parley  
Home Address

Mr J Stuart  
General Manager  
Mental Health Services  
Royal Cornhill Hospital  
26 Cornhill Hospital  
Aberdeen  
AB25 2ZH

Date 1  
Your Ref  
Our Ref FP4/26/08

Enquiries to Fiona Parley  
Extension XXXXX  
Direct Line XXXXX XXXXX  
Email: [xxxxx@xxxxxxxxxxxxx](mailto:xxxxx@xxxxxxxxxxxxx)

Dear Mr Stuart

### **Research – Abuse of Vulnerable Adults**

As you are aware I have commenced a research degree as a self funding student exploring the above subject. You will appreciate the sensitive nature of the subject matter and I therefore write to request permission to use my work address for mailing purposes.

The subjects in the study are staff working within learning disability care services and I would hope to interview them during their paid work time. I would be grateful if you would consider granting work time for the conduct of interviews.

Yours sincerely

Fiona Parley  
Nurse Manager



Grampian Primary Care NHS Trust

Management Office  
Fulton Clinic  
Royal Cornhill Hospital  
Cornhill Road  
ABERDEEN AB25 2ZH  
Tel: (01224) 557314  
Fax: (01224) 557488  
Email: jack.stuart@gpct.grampian.scot.nhs.uk



Date 6<sup>th</sup> June 2003  
Your Ref  
Our Ref: js/mb/lett/561

**In Confidence**  
Ms Fiona Parley

Dear Fiona

**Research – Abuse of vulnerable adults who have learning disabilities**

Further to your letter of 2<sup>nd</sup> June on the above subject, I now write to confirm my agreement to using your work address, Woodlands Hospital, for correspondence in connection with your study and also the use of Trust headed notepaper for this purpose.

Furthermore, I agree to your request for paid leave for interviews of research subjects.

May I take this opportunity to wish you well in your research project.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Jack Stuart', written in a cursive style.

Mr Jack Stuart  
**General Manager**