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Am I there yet?

**The views of people with learning disability on forensic
community rehabilitation.**

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Doctorate in Clinical Psychology

University of Edinburgh

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I declare that I am the sole author of this thesis and that the work contained herein is my own. This thesis or any part of it has not been submitted for any other degree or professional qualifications.

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Abstract

Introduction: Previously diversion from the criminal justice system for people with LD and forensic needs had meant hospitalisation, but more recently a model of community-based rehabilitation has become possible via new mental health legislation. Community-based orders aim to rehabilitate clients via compulsory, intensive staff support. Although this model is beneficial in theory, empirical evidence suggests there may be a number of issues in practice. The current study aimed to capture the subjective experience of a group of individuals with LD and forensic needs currently on community-based orders.

Method: Semi-structured interviews were conducted with ten participants subject to a community-based order which obliged them to accept intensive staff support. All participants were male. Ages, index behaviour, and time spent on order varied. The data was transcribed and analysed using Interpretative Phenomenological Analysis.

Results: The main themes which emerged from the data were *A taste of freedom*, *Not being in control*, *Getting control back*, *Loneliness*, and *Feeling like a service user*. Overall the results indicated a general ambivalence towards support.

Discussion: Participant accounts suggest that the current community rehabilitation model has some shortcomings which need to be addressed. The system as it stands appears to promote high levels of external control, failing to empower clients to self-manage. Suggestions are made for improvements to the current model relating to: achieving clarity over the role of support staff and pathways out of the system; increasing opportunities for service users to voice concerns; empowering staff teams via extensive training and supervision; and directly addressing internalised stigma to promote integration.

1 Introduction

1.1 Learning disability and offending behaviour

The definition of a learning disability (LD) requires the fulfilment of three criteria: an individual's IQ must be 2 standard deviations below the normal population (70 or less); they must need help with 2 or more areas of daily living; and the onset of their difficulties must have begun before the age of 18 years (American Psychiatric Association, 2000).

Prevalence rates of offending in the LD population have been difficult to accurately measure. The reasons behind this are numerous including the variation in the definition of a LD across studies, the accuracy of the tests used to diagnose the individual, and which part of the criminal justice system is being looked at (Holland, 2004).

Offences do not necessarily mirror arrests or convictions in this population as a lack of criminal intent (*mens rea*) may be assumed due to their cognitive impairment. Behaviour may therefore be labelled as 'challenging' rather than criminal (Holland *et al.*, 2002). In addition carers for people with LD are less likely to report crimes committed by their service users, and offences where the victim also has LD are less likely to be reported (Thompson & Brown, 1997). Even when cases involving an individual with LD are reported, and result in a charge, issues around competency to confess, competency to plead, competency to stand trial, and diminished responsibility may mean the charges are not upheld (Holland, 2004).

For all these reasons prevalence data has been extremely difficult to decipher with authors reporting estimates ranging from zero in a study of prisoners on remand (Murphy *et al.*, 1995) to a quarter of those appearing in court (Barron *et al.*, 2002). Considering that people with LD form approximately 2 per cent of the population

(Scottish Executive, 2000a) the latter would be a huge over-representation. Despite the variation, reviews of the literature indicate that the majority of studies do find that people with LD are overrepresented in at least some areas of the criminal justice system (Lindsay, 2009).

If this overrepresentation is genuine it is likely to be mediated by other factors, for example, exposure to low socio-economic factors or decreased ability to avoid being apprehended (Lindsay, 2009). Whatever the proportion, people with LD and forensic needs are a significant group and the differentiation of their care and treatment is a legitimate concern.

1.2 Principles of community rehabilitation

For people with LD who are seen as a significant risk to the public an active process of diversion, from the criminal justice system into the health and social care system, has been employed since 1990 in the UK (Bradley Report, 2009). A review carried out by the government almost 20 years ago (Reed Report, 1992) made clear that prison was not an appropriate setting for mentally disordered offenders (MDOs) (those with mental health difficulties or LD) and that they should instead receive access to health and social care in order to be rehabilitated back into the community.

Community rehabilitation for people with LD and offending histories has lacked a framework until recent years. The development of community-based services for people with LD and forensic needs has largely been a product of mental health reform in Scotland, but has also occurred in the context of mass deinstitutionalisation within generic LD services.

1.2.1 Mental health reform

In 2001 the Mental Health (Scotland) Act 1984 was reviewed by a government committee led by Rt. Hon. Bruce Millan as a first step in the overhaul of mental health services in Scotland. The committee produced a report, commonly referred to as the Millan report, outlining the principles on which new mental health services should be based (see figure 1).

- 
- Non- discrimination
 - Equality
 - Respect for diversity
 - Reciprocity
 - Informal care
 - Participation
 - Respect for carers
 - Least restrictive alternative
 - Benefit

Figure 1 Principles of mental health reform as outlined in the Millan report (Scottish Parliament Information Centre, 2002, p. 4-5)

The review focused on increasing community-based care and use of informal care where possible.

The new mental health legislation which resulted from the Millan report, the Mental Health (Care and Treatment) (Scotland) Act 2003 (hereafter MHA 2003), provides the legal backbone for forensic community care. It both introduced Community Treatment Orders (CTOs), and amended the Criminal Procedures (Scotland) Act (1995) to allow similar orders, Compulsion Orders (COs). Both these types of orders allow an individual to be returned to the community under a number of conditions which may include: where they live; the professionals they must allow to visit them at their home; and the treatment they must receive. In practice 'treatment' is broadened beyond medical intervention to include psychological interventions and acceptance of, often intensive, levels of staff support.

The MHA 2003 also advised the use of Guardianship Orders, (GOs) as outlined in the Adults with Incapacity Act (2000), as a longer-term measure. This means that a professional guardian is appointed, usually a social worker, who can place conditions on the individual. Similar to community-based orders this may oblige the client to reside in a certain area, to accept staff support, and to attend medical appointments. These changes have provided leverage via which health and social care professionals can insist on engagement from clients living in the community in order to adequately manage risk, as they could only previously do with patients detained in hospital. It also means that even if an individual has not been convicted of an offence they can still be placed on a civil order (CTO, GO) if their risk of offending is considered great enough.

There is no specific time limitation on these orders, although they are required to be reviewed at regular intervals. CTOs and COs must be reviewed after 6 months and then yearly thereafter; GOs have a default period of 3 years although the court has power to reduce or extend this, including the power to make the order indefinite. For any of these orders the individual on the order, or select others, can contest the order if they feel their circumstances have changed sufficiently.

The implementation of these pieces of legislation has introduced a framework for delivering forensic rehabilitation in the community. This means that a person with LD and forensic needs, who would be inappropriately placed in prison or hospital, can be offered a community placement.

1.2.2 Deinstitutionalisation within generic LD services

Concepts of normalisation (Nirje, 1969), social value (Wolfensberger, 1972), and inclusion have shaped current thinking with regard to people with LD, impacting

on policy and service development in the UK (Department of Health, 2001a; Scottish Executive, 2000a).

A review of the services received by people with LD across Scotland, *The Same As You?*, was carried out in 2000 (Scottish Executive, 2000a). This revealed the continued social exclusion and lack of opportunities for choice and autonomy of people with LD. The recommendations of the review were concerned with increasing access to mainstream services for people with LD and reducing LD specialist services, including long-stay hospitals. Tangible targets were set within this document for hospital closures and this began mass deinstitutionalisation.

A subsequent report (Scottish Executive, 2004) outlined that agencies should work with care providers to ensure appropriate community services were available for those leaving hospital, in particular those with more complex needs, including the forensic population.

As well as providing part of the context for the set-up of community services for people with LD and forensic needs deinstitutionalisation has created a body of literature on the expected and actual outcomes of community living. This empirical evidence will be referred to throughout as it provides a helpful parallel for the development of forensic community services for people with LD.

1.3 Community-based forensic services

Rehabilitation models used within LD services are generally adapted versions of those offered to the mainstream population (e.g. Keeling *et al.*, 2009). The following section will review the development of these models over the last few decades

looking at the change in approach and how this has paved the way for a community-based model.

Although general models of offending will be considered, both in the following section and throughout the chapter, there will be a particular focus on models of sexual offending. This is due to the fact that sexual offending is thought to be an overrepresented area of offending within LD forensic populations (Barron *et al.*, 2004; Day, 1988; Walker & McCabe, 1973). Sexual offending, particularly against children, has also been associated with lower IQ (Cantor *et al.*, 2005).

1.3.1 The evolution of offender rehabilitation models

Approaches to tackling offending behaviour have evolved over the years, no doubt in response to changing societal views and developing research. The effectiveness of these approaches was called into question in the 1970s when research seemed to show that intervention with offenders was as likely to fail as to succeed. This culminated in a review of 231 studies and a declaration by one of the authors that 'nothing works' in the field of treating offending behaviour (Martinson, 1974). Although Martinson's study was eventually discredited, even by Martinson himself (Martinson, 1979), at the time this movement triggered further study into how offender rehabilitation could be successfully implemented.

In the 1980s and 90s, as more authors began to investigate how interventions were applied and which groups they were applied to, there appeared to be a turnaround (Gendreau & Ross, 1987). The Risk-Need-Responsivity (RNR) model in particular seemed to offer new hope that if interventions were implemented according to the level of risk the individual presented, aimed to target specific identified criminogenic needs, and were flexibly applied on an individual basis, treatment

success was significantly increased (Andrews *et al.*, 2006). The focus remained, however, on exploring the offence in detail and working on reducing what were considered to be dynamic risk factors in individual therapy, for example empathy deficits, distorted cognitions and deviant sexual arousal (McMurrin & Ward, 2004).

This risk-based approach stems from a relapse prevention model, as advocated by correctional agencies, and a number of difficulties arise from this (McMurrin & Ward, 2004). As reducing risk is the sole aim of treatment, goals are not shared with the individual and this has implications in terms of client engagement and responsiveness to treatment (McMurrin & Ward, 2004; Ward & Mann, 2004). The focus of the intervention was also entirely on the eradication of risk-related behaviours without considering the function of these behaviours. Therefore, once these behaviours were successfully eradicated, the individual was left with unmet needs. Without the parallel development of pro-social ways in which to meet these needs, a return to offending was more likely (Ward & Mann, 2004). Finally a risk-focused model fails to see the individual as a complex entity, driven by different motivations, and therefore encourages a blanket approach to treatment (Ward & Mann, 2004).

These criticisms have ushered in a new wave of models which offer more integrated explanations of offending behaviour, in particular sexual offending, focusing on the individual's wider context: Integrated Theory (Marshall & Barbaree, 1990); Integrated Theory of Sexual Offending (Ward & Beech, 2006); and the Good Lives Model (Ward & Brown, 2004). These theories give more weight to a broader understanding of offending in terms of the impact of early experiences, the development of coping strategies and attitudes, and the possible elements of the individual's present context which may be maintaining their difficulties.

This is in line with recent research which suggests that criminogenic risk factors encompass both individual factors, such as offence supportive attitudes, and also wider contextual factors, such as a lack of intimate relationships and negative social influences (Mann *et al.*, 2010). Reviews of the literature have also revealed that some of the person-specific risk factors which have traditionally been the focus of intervention programmes, such as denial and victim empathy, have a weak relationship with recidivism, if any (Mann *et al.*, 2010).

In parallel there is an ever-growing literature on the importance of environmental protective factors, such as positive social support mechanisms and meaningful activities, which help to reduce recidivism by changing the individual's sense of identity or personal narrative (Maruna, 2001). This emphasised that 'treatment' should form just one component of a wider risk management plan and that interventions should become more focused on building capacity and increasing social networks as well as addressing risk factors.

New models of offending behaviour have therefore broadened the intervention goals, aiming to help individuals to improve their lives rather than just reduce their anti-social behaviour (Ward & Mann, 2004). This shift in focus from reducing deficits to improving quality of life is paralleled within mental health services as reflected in both the recovery movement within mental health and growth of 'positive psychology' (Anthony, 1993; Linley & Joseph, 2004).

1.3.2 The community-based model for people with LD and forensic needs

In designing the model of community-based care for clients with LD and forensic needs, the challenge for NHS boards and local authorities was to construct services which adhered to the principles of empowerment and equality reflected in the Millan principles while still maintaining public protection.

In preparation for the changes in service delivery across Scotland a number of steps were taken by health and social work agencies in relation to MDOs, including those with LD. In 1999 the NHS Management Executive Scotland outlined the Scottish Executive's policy on MDOs (NHS Management Executive Letter, 1999). The paper was clear that although public safety was important, the ethos of community care should be focused on meeting the needs of the individual and giving them the best chance of being rehabilitated back into society.

The forensic managed care network (MCN) set up a working group in 2005 who were asked to establish guidance for how services for forensic LD clients across Scotland should be set up. The recommendations are shown in figure 2.

- Development should focus mainly on the development of **community** provisions.
- **Robust, flexible** services are needed
- **Joint working** is needed between social work, health, housing and social care providers.
- Specialist residential placements with high-standard accommodation allowing for **close supervision and monitoring** is required.
- **Specialist care providers** should deliver care plans agreed by specialist **multi-agency teams** who are set-up to support these placements.
- There should be **links between different levels of security** including community services and with other involved agencies – police, Criminal Justice, courts, prisons.
- Access to **independent advocacy** should be available.

Figure 2 The principles on which the set-up of forensic LD services should be based (Forensic Mental Health services MCN, 2005, emphasis added)

The ‘how’ of balancing public protection with community-living was to be achieved through the development of specialist care packages within residential placements. Specialist care providers would provide social support to these clients and they, in turn, would receive support and advice from specialist multi-professional teams. The ethos of these care packages was clearly stated.

Care packages and training programmes (for care providers) should be centred around values, respect, be demonstrably therapeutic and again

strive to promote social inclusion. (Forensic Mental Health services MCN, 2005, p.21)

1.3.3 Promoting Good Lives

One of models at the forefront of the positive approaches movement in forensic populations is the Good Lives Model (GLM). GLM is a model of offender rehabilitation advocated by Professor Tony Ward and colleagues. Ward posits that all humans strive to meet the same basic needs, or 'primary goods' and that all human activity is ultimately designed to meet one or more of these ends (e.g. Ward & Brown, 2004). The primary goods are drawn from social science, psychology, anthropology, and evolutionary theory and are shown in figure 3 below.

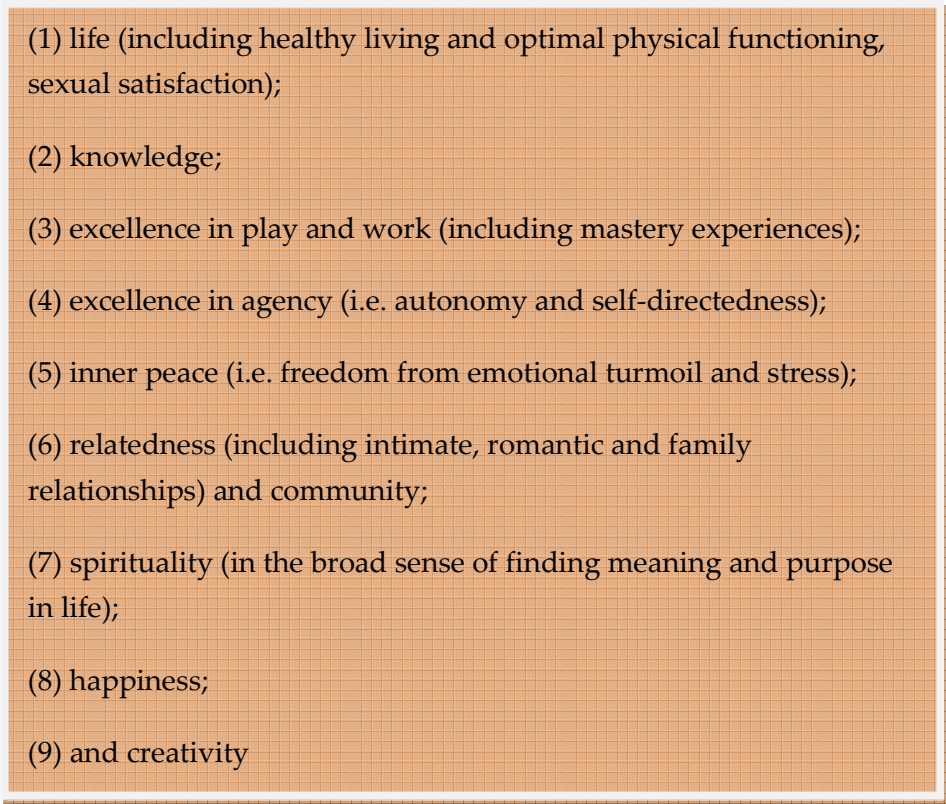
- 
- (1) life (including healthy living and optimal physical functioning, sexual satisfaction);
 - (2) knowledge;
 - (3) excellence in play and work (including mastery experiences);
 - (4) excellence in agency (i.e. autonomy and self-directedness);
 - (5) inner peace (i.e. freedom from emotional turmoil and stress);
 - (6) relatedness (including intimate, romantic and family relationships) and community;
 - (7) spirituality (in the broad sense of finding meaning and purpose in life);
 - (8) happiness;
 - (9) and creativity

Figure 3 Ward's nine primary goods (Ward & Brown, 2004, p.247)

These ideas are not new. They have echoes, for example, of the principles of normalisation within LD services. Normalisation relates to the right of people with a LD to access the same opportunities as any other individual within a society. The concept was first introduced by Nirje (1969) based on elements of Danish law which were encouraging equal standards to be applied to people with LD, or mental retardation as it was referred to at the time. The normalisation principle as Nirje saw it was that people with LD had entitlement to certain aspects of life, as outlined in figure 4.

- A normal **rhythm to their lives**, including a normal daily routine, a normal yearly routine, e.g. annual holidays, a normal life - living in one area with structure around them but also a degree of flexibility;
- Access to the **normal developmental experiences of the life cycle**, for example to be cared for by others, then move towards independence, and be treated with dignity in elder years;
- To have the ability to **make choices**, to have their wishes taken into consideration;
- To live in a **bisexual world**, of both male and female staff and have the option of co-habitation and marriage with a partner;
- To live within **normal economic standards**, either through work or government endowment;
- To have a similar **standard of living** to those of others in the mainstream population

Figure 4 A summary of the basic entitlements of people with LD
(Nirje, 1969, emphasis added)

O'Brien, similarly, attempted to provide a definition of the concept of a 'normal' life, which people with LD were entitled to, and identified five areas he considered were vital. These were community presence (going to everyday places within the

local community), choice (autonomy), competence (being able to achieve meaningful activities), respect (being valued), and community participation (being part of a wider social network). These became better known as the Five Accomplishments (O'Brien, 1987).

There is significant overlap between these theories, suggesting general agreement about the principles which improve quality of life. Ward posits not just that these are core human needs but that it is the failure to achieve these in appropriate ways, and a resulting attempt to meet them in other ways, which leads to offending. For example a search for relatedness might lead most of us to develop positive friendships but, if these are not available, it may be pursued through joining a gang, which in turn may then lead to criminal activity. Sexual needs may be best met through a consensual partnership but if this cannot be accessed the need remains and could potentially be met through the use of sexual force.

There may be a number of reasons why individuals cannot access primary goods in appropriate ways including lack of access or skills, lack of scope in pursuing only a narrow selection or a conflict between desired goods (Ward & Stewart, 2003; Ward & Mann, 2004). The GLM proposes that in order for an individual to change their anti-social behaviour there must be: a clear formulation of the needs being met through offending; they must be presented with alternatives to meeting these needs; and they must be supported in acquiring the skills and access to achieve this alternative (Ward, 2002; Ward & Brown, 2004).

Backing for this more positive, or rehabilitative, approach has been useful in terms of considering an individual's engagement with intervention. The impact of engagement on treatment outcomes has been recognised more in recent literature, mainly led by Mary McMurrin and colleagues (e.g. McMurrin, 2002). McMurrin

argues that individuals will be more likely to engage in interventions which aim to help them improve their situation, rather than those which focus solely on reducing offending (McMurrin & Ward, 2004).

Although Ward's model was designed with reference to a mainstream (non-LD) client group it applies particularly well for individuals with LD who often have difficulties with communication and social skills, as is the nature of their impairment. This can limit their access to social and vocational opportunities which would, in theory, help them achieve these primary goods. The GLM may therefore provide a framework to bring together the goals of individualised rehabilitative care and risk management, for the purposes of public safety, in LD offenders (Aust, 2010).

Community rehabilitation also fits particularly well within this model as opportunities to achieve the outlined primary goods are increased. In their review of the literature Emerson and Hatton (1994) concluded that deinstitutionalisation for people with LD would provide:

- Material standard of living/less institutional setting
- Support & satisfaction with services
- Opportunities to develop skills/competencies
- Opportunities for choice
- Opportunities to develop relationships/social network
- Community presence/sense of belonging
- Time engaged in meaningful activity

All of these map well onto Ward's primary goods, suggesting that a community model would be effective in increasing quality of life and, according to the GLM, indirectly reducing offending behaviour.

A related concept is Maslow's hierarchy of needs (e.g. Maslow, 1998). Maslow described human needs as being organised in a staged fashion, suggesting that only when more basic needs have been met can other, higher level, needs begin to be addressed. Once basic needs (food, water, shelter) are intact the individual can begin to consider the next level (safety and stability-related needs), and once these were fulfilled they would be in a position to consider relationship needs, then esteem-related needs (mastery, achievement, responsibility) and finally, the individual could strive for self-actualisation (personal growth and fulfilment of one's potential).

Basic needs and those related to survival and stability would perhaps be expected to be achieved both within a hospital setting and a community setting. Community living, however, with its increased social and vocational opportunities, might be expected to allow individuals to reach a higher level of needs and allow a process of self-actualisation to begin. This, in turn, may promote rehabilitation in terms of the forming of a new self-identity or self-narrative following a period of personal growth and development as discussed within desistance literature (Haaven *et al.*, 1990; Maruna, 2001).

This promotion of self-identity may also facilitate rehabilitation via another route. Self-actualisation is described by Maslow (1998) as the ability to express the latent parts of ourselves and to *gain distance from our own needs*. Before we reach this self-actualised state he claims that 'D-cognitions' (deficit-cognitions) predominate

within us (p.195). These are 'selfish' cognitions which view the world as a collection of 'gratifiers' or 'frustrators' of our needs, rather than viewing these objects in their own right (p.195). This self-involved, gratification-based orientation is reminiscent of that described in individuals who commit sexual offences (Marshall & Barbaree, 1990). During the process of self-actualisation Maslow states that 'B-cognitions' (being-cognitions) (p.195) take over as the dominant way of thinking, signalling a distancing from our immediate needs, a sense of self-acceptance, and an ability to view relationships in a more balanced way.

1.3.4 Community living as directly addressing dynamic risk factors

In line with the GLM community living seems to address a number of specific risk factors connected to offending. A few of these are worth outlining in more detail and are helpfully summarised by Lindsay (2005).

Quality of life of offenders becomes a central issue in their treatment. If the individual has, for example, an impoverished quality of life, with low levels of personal relationships, lack of pro-social influences, poor community integration, impoverished housing, one would predict [...] that it would increase the likelihood of sex offending and recidivism.
(p. 436)

1.3.4.1 Social isolation

Marshall and Barbaree's (1990) influential model was the first to formally introduce the concept that sexual offending was the product of poor parenting and a resultant inability to form relationships in adolescence and adulthood. In agreement with this theory various studies have found an association between sexual offending and damaging developmental environments (Day, 1988; McCormack *et al.*, 2002); insecure attachment patterns (Ward *et al.*, 1996; McCormack *et al.*, 2002); high levels of loneliness; and low levels of psychosocial intimacy (Garlick *et al.*, 1996).

Feelings of loneliness have also been shown to be a precursor to the onset of deviant sexual fantasies, which in turn increase the individual's risk of offending (McKibben *et al.*, 1994). Cortoni and Marshall (2001), similarly, found that sexual offenders were more likely to use sex as a coping mechanism in the face of negative emotions and that those with higher scores on loneliness and intimacy scales showed even greater use of sexualised coping.

Within LD populations the counterfeit deviance hypothesis has suggested that, rather than deviant sexual preferences, it is poor social skills and inability to form appropriate relationships (coupled with a lack of sexual knowledge) which leads to sexually inappropriate behaviour (Hingsburger *et al.*, 1991). Findings from Steptoe *et al.* (2006) support this theory. They compared people with LD who had committed sex offences and a group of non-offenders with LD. Although both groups had similar access to social opportunities those with offending histories did not make use of these opportunities to the same degree, indicating core difficulties in forming relationships.

The importance of social capital (valued relationships, societal belonging) in addition to human capital (personal resources) is becoming increasingly recognised (Farall, 2002; McNeill, 2009). Although individual work with offenders can address the latter, the former is more difficult within a clinical setting. Community living provides increased access to a range of social opportunities and therefore potential to form new relationships (Emerson & Hatton, 1996). If the individual is able to consolidate these relationships there is potential for decreased loneliness and, consequently, a reduction in risk.

1.3.4.2 Disengagement with societal values

According to control theory disengagement with the views and morals of society will have a major impact on criminal propensity (Hirschi, 1969). Indeed anti-social orientation has been demonstrated as a significant risk factor in sexual offending and in general recidivism (Hanson & Morton-Bourgon, 2004).

The development of anti-social views is thought to be the result of unstable family environments (e.g. Farrington, 1995). Households with poor parenting practices model and reinforce the use of negative and anti-social coping strategies (e.g. aggression, non-compliance) (Patterson, 1986). The use of such coping strategies results in not only disrupted parent-child bonds but difficulty with schooling and peer interaction. This, in turn, prevents the child from accessing positive mediators or developing alternative means of interacting, consolidating these attitudes (Patterson, 1986).

Social cognition theory proposes that we all use our attitudes or cognitive biases as a way to organise the world and, more importantly, to maintain our own self-esteem (Cummins & Nistico, 2002). For those with backgrounds of abuse or neglect, these biases may become quite distorted to allow the individual to adjust to these environments (Cummins & Lau, 2004). This may in turn lead to maladaptive cognitions which serve to justify or perpetuate anti-social behaviour, for example seeing the world as a dangerous place; having a sense of over-entitlement; seeing children as sexual beings; and so on (Mann & Beech, 1993).

Clark (2011) proposes that certain types of cognitive distortions allow offenders to avoid consideration of the negative effects of their actions. She argues, however, that '...offenders are not immune to the conforming norms of society' (p.2), and that what is learnt can be unlearnt. If cognitions serve principally to maintain self-

esteem, then situations could theoretically be created in which the offender can form a positive self-image based on pro-social activities and relationships. If this occurs then these cognitions should no longer be needed and should begin to decrease.

Lindsay (2009) makes the case that segregating individuals within secure settings perpetuates disengagement with the values of society. He argues that by integrating these individuals within the community they are provided with consistent 'reality checks' which make the maintenance of anti-social cognitions more difficult. Community interactions may even serve to challenge some of the cognitive distortions held by the individual, for example through holding a valued role or developing a trusting relationship.

1.3.4.3 Opportunities for meaningful occupation

The positive effects of occupation on desistance are well known (Maruna, 2001). The opposite is also true, in that unemployment and unstable lifestyle are both linked to recidivism (Hanson & Morton-Bourgon, 2004) explaining why vocational and work initiatives remain so important for those exiting correctional settings (e.g. Wilson *et al.*, 2000).

Lindsay (2009) makes the basic argument that people need to fill their time and if this is not with something pro-social, the risk increases that they will turn to anti-social pastimes. Self-reports from LD service users indicate that the experience of supported employment is positive in that it provides structure and a sense of participation in the community (Cramm *et al.*, 2009).

The opportunities for meaningful activity, whether this is in the form of employment or something equally meaningful to the individual (e.g. educational

placement), seems important and again one with limited scope within a hospital setting.

1.3.4.4 Internal control

The concept of internal control relates to an individual's perception that they are able to exert control over their own environment or behaviour. This is related to the concepts of self-efficacy (belief in one's own capabilities), autonomy, and offence-related issues of responsibility and self-management. High levels of external control (i.e. feelings of little control over environment or behaviour) and related traits have frequently been documented within offending populations and is thought to be related to abusive childhood environments, in particular, experiences of physical abuse (Fisher *et al.*, 1998).

External locus of control has been found to be related to higher rates of offending in general (Fisher *et al.*, 1998). Both violent offenders and sexual offenders have been found to have a tendency to externalise blame for their offending, often placing the blame with victims (Garlick *et al.*, 1999; Gudjonsson & Sigurdsson, 2004). Poor impulse control and need for immediate gratification have also been noted as a core component of both violent and sexual offending (Farrington, 1995; Gottfredson & Hirschi, 1990), and self-regulation is a significant factor in sexual recidivism (Hanson & Morton-Bourgon, 2004).

The field of locus of control and self-regulation is an under-researched area within LD populations who offend (Goodman *et al.*, 2007). Fisher *et al.* (1998), however, did report that locus of control was related to IQ, in that a more internal locus of control was related to higher IQ scores, suggesting there may be a link.

Another important finding is that interventions do not seem to improve locus of control for people with LD and sexual offence histories (Rose *et al.* (2002; Langdon

& Talbot, 2006). Rose *et al.* (2002) explained this in terms of the frequent contact these individuals had had with bodies of external control, that is, correctional agencies. There may be other ways of interpreting this finding, however, in terms of the limited transferability of skills outside of an intervention context (Rice & Harris, 1997). Opportunities where individuals are able to increase their internal feelings of control *in vivo* may be necessary to supplement individual interventions.

Again, there appears to be greater scope for the promotion of internal control and self-management within a community setting. If individuals are in an environment which provides more freedom of movement than opportunities for choice, independence and responsibility should increase as should self-efficacy and internal control as a result.

Hall & Hirschman (1992) have suggested that a 'threat threshold' needs to be reached before individuals will attempt to self-regulate. If the lives of these individuals are empty and unfulfilling then the loss of this may pose very little threat (Lindsay, 2009). If they are able to gain more meaningful occupational interests, roles and relationships then this 'threat threshold' may reduce.

1.4 The challenges of delivering these benefits in practice

1.4.1 Community integration

It seems unclear whether the assumed benefits of community living can spontaneously materialise. Individuals on community-based orders will, in most cases, have had a period of living in hospital prior to gaining their own tenancy. This means they are likely to have some of the same adjustment issues as psychiatric patients who leave hospital. Various studies have reported that people

with mental health difficulties who move out of psychiatric institutions struggle to achieve a sense of belonging within the communities they move into.

Prince and Prince (2002) found that high levels of physical integration in psychiatric patients did not lead to a sense of belonging within the community. Other studies have shown that even if a sense of belonging can be fostered it may not lead to improved outcomes. Aubry and Myner (1996) found that physical integration and a general sense of community presence did not bring with them improved quality of life or increased social contact. Gerber *et al.* (2003) reported outcomes for a forensic psychiatric population in Canada. They found that quality of life was slightly improved for this group but that individuals continued to avoid social settings, and, despite reporting a sense of belonging in the area, did not expect to stay there long and were unperturbed by the idea of moving elsewhere.

Issues of stigma and exclusion from social and vocational opportunities are rife for these individuals, as they are for the study population, and, where opportunities for engagement with the community do present, there are further issues in relation to disclosing their histories (Barnham & Hayward, 1991).

Cummins and Lau (2003) discuss the concepts of 'community integration' as opposed to 'community exposure' for people with LD (p.145). Assumptions can be made about housing someone within a pre-existing community, however, these are individuals who unlikely to immediately and easily fit in. LD in itself can be a barrier to communication and integration but with a forensic client group there are additional obstacles. Not only is this a group of individuals with complex emotional difficulties (Barron *et al.*, 2004) but their behaviour has been, by its very nature, 'anti-social' and they may not be welcomed by the local community into which they are placed. This is particularly poignant for those committing more socially

unacceptable crimes, such as sexual offending, who report experiencing high levels of community hostility (Brannon *et al.*, 2007).

1.4.2 Developing a social network

Ideally a community placement would not just help people to feel generally more included in society, it would also present more social opportunities and a widening of that individual's support network. In reality people with LD, even those without the additional restrictions associated with having a forensic background, report finding it very difficult to develop appropriate relationships while being supported. This is due to not only a lack of interpersonal skills but also perceived interference by staff and a general lack of privacy (Hollomotz, 2009).

It is worth reflecting again on the attachment difficulties noted in offenders (McCormack *et al.*, 2002) and the impact these may have on the development of potential relationships. The finding by Steptoe *et al.* (2006) is also significant here in that people with LD and sexual offending histories find it difficult to develop friendships even when opportunities are available.

The principles of normalisation, which remain prominent in LD services, can also create a barrier as service users are encouraged to veer away from their natural peer group in favour of relationships with normally developing adults. For example, government documents make reference to the perception that a person is at a disadvantage if they do not have contact beyond their family and peers of similar cognitive ability.

Social Isolation remains a problem for too many people with learning disabilities. A recent study found that only 30% had a friend who was not either learning disabled, or part of their family or paid to care for them. (Department of Health, 2001a, p.20)

Normalisation was a concept used to argue for people with LD to live in society rather than within institutions, and should not be overgeneralised to the more complex integration issues which exist now. It is common practice for people to naturally group with those they feel similar to, for example migrants form their own communities within cities and older people live together in retirement villages (Cummins and Lau, 2003). It seems wholly natural to associate with people of a similar intelligence, with shared lifestyles, interests and identities. This raises the question of whether or not it is 'normal' to expect people to associate with those who are socially and intellectually more able. Although this type of inclusion of people with LD may well benefit other groups, for example giving tangible goals to service providers and normalising disability in the general public, this is not to say it benefits the individuals directly.

1.4.3 Increasing autonomy

Policy initiatives tend to give little guidance on the difficult area of how principles of maximising choice and empowerment can be applied to people with LD and forensic backgrounds (Beacock, 2005). The population in question is both subject to legal detention, restricting their liberty, and their needs must always be balanced with public protection (Aust, 2010). Although more opportunity for choice and independence may well exist in a community setting, these freedoms may not be accessible for this group. Community orders were created as a 'least restrictive alternative' however the fact that they compel individuals to adhere to treatment and to live within certain restrictions has led to questions about whether or not this is an infringement of human rights (Snow & Austin, 2009). In fact, contrary to offering more freedoms, the high degree of supervision in these orders has led practitioners to refer to these types of services as 'professional paternalism' (Lawton-Smith *et al.*, 2008, p.97) or 'therapeutic stalking' (Graham, 2006, p. 41).

An additional difficulty is that although there is a consistent drive to move individuals from hospital into the community, there appears to be less commitment to moving people on following this. Community-based legal orders must be reviewed regularly however they do not have a specified end date. Concerns have therefore been expressed over the potential for 'compulsion creep', that is, that although numbers of people in hospital may be dropping, those on orders stay on them for a longer duration, causing an overall increase in the numbers of individuals subject to compulsory care over time (Jackson, 2007). This means that we are simply shifting the problem from one care setting to another rather than creating a successful rehabilitation pathway (Lawton-Smith *et al.*, 2008).

Lawton-Smith *et al.* (2008) also raise concerns about the evidence base for the rehabilitative effects of community orders. Indeed, the outcomes of the few studies which have been carried out have been unable to demonstrate any clinical advantage. A Cochrane review was carried out based on the only two randomised studies available, both in the USA, and revealed that CTOs used with psychiatric patients did not improve patient outcomes, quality of life, social functioning or satisfaction with the service (Kisely *et al.*, 2005).

1.5 Delivering the model via intensive staff support

1.5.1 The potential for non-therapeutic relationships

The centrality of staff-client relationships within forensic settings is reflected in service user accounts. Godin and colleagues, with funding from the National Programme on Forensic Mental Health Research & Development, set out to explore service user experience of forensic mental health services (Godin *et al.*, 2005). They

found that service users were concerned about a number of issues in forensic services but consistently referred to the importance of their relationship with staff.

[service users] were also concerned that their relationships they had with staff were often far from therapeutic. They described staff as frequently lacking trust, loyalty, honesty, compassion and any respect for patients. (Godin *et al.*, 2005, p.6)

Service users commented that the best improvement that could be made to services was making the relationship between patients and staff more therapeutic.

Although this study was in relation to forensic mental health, rather than an LD population, there is likely to be considerable shared experience between these two groups. The relationship between staff and clients in LD has often been a neglected area of study, although it has a huge impact on the service being delivered (Hall & Hall, 2002). Service users with LD consistently report the importance of their relationship with support staff (Clarkson *et al.*, 2009). This may be in part because many have limited social contact beyond the professionals that work with them (Emerson *et al.*, 2005). For those under legal orders in the community, support staff will be present for large periods of the day, often twenty-four seven, further increasing the importance and potential impact of their interactions with the client.

1.5.1.1 The impact of managing a dual role

The power imbalance between people with LD and those who provide their support is well-noted (Conway, 1994). This imbalance is likely to be exacerbated when there is a conflict between the primary staff role of supporting the individual and a secondary supervisory or risk management role (Schafer & Peternelj, 2003). This role conflict has also been noted in other services that need to balance support and supervision, for example with individuals who self-harm (Duperouzel & Fish, 2008).

Schafer & Peternelj-Taylor (2003) point out that, for forensic patients, the power differential between staff and client is even greater, due to the risks the patient poses and the level of management required. They argue that the vulnerability of this group becomes lost at times.

The management of this dual role, of support and supervision, has been the focus of a number of studies, with many authors finding that this presents a significant challenge.

[studies show]...contradictions inherent in, and dilemmas arising from, the nurse's dual role of creating a therapeutic relationship while managing aspects of risk.(Hinsby & Baker, 2004, p.342)

These studies have mainly been conducted in ward environments, looking at the interactions between nurses and patients. Despite this difference in setting and profession many of the issues can be validly generalised to support workers and clients in the community, especially in the context of an intensive or twenty-four seven support package. Hinsby & Baker (2004) for example interviewed male nurses and patients on a medium-secure unit about violent incidents that had occurred on the ward. They found a general theme of 'control' in patient-nurse relationships. There was little mention of the function or meaning of the aggressive behaviour and little or no mention of prevention strategies. Management, unpredictability and risk were paramount. The authors also observed that staff and patients seemed to allude to a pseudo-family of: the distant, knowing father (psychiatrist); the rule-implementing mother who reports back to father (nursing staff); and the uncontrolled child (patient).

Gildberg *et al.* (2010) conducted a review of staff-patient interactions in forensic psychiatric nursing. They found a similar tendency for care in these settings to be thought of as parental in nature with the nursing staff interpreting their role as

observing, controlling, and confronting the patient in order to implement behaviour change.

There seems to be a striking difference in the interpretation of staff and patient views on the best means of resolving conflict or managing challenging behaviour. Duxbury (2002) found that patients were more likely than staff to think that de-escalation could be successful when conflict arose (Duxbury, 2002). Whereas staff members tended to make reference to inpatients' internal state as the trigger for aggression, patients were more likely to cite environmental factors (Duxbury, 2002). This means that, in the main, patient behaviour was 'managed', the environment remained unchanged, and the problem was seen as existing solely within the individual, reinforcing a culture of blame.

Conflict may be more likely to arise due to the interactions between staff and patients. There is evidence to suggest that verbal interactions used with forensic clients are more confrontative than in general psychiatric care, and that nursing staff feel it is part of their role to encourage the patient to talk about their criminal behaviour (Rask & Levander, 2001). This is despite the increased stress this may cause and the lack of evidence that it proves useful (Rask & Levander, 2001). Interestingly, although staff did not consider their actions punitive, they were experienced in this way by patients (Hinsby & Baker, 2004).

Concerns about risk with this group are a major influence on staff practice. In Hinsby & Baker's (2004) study staff considered using flexible decision making more risky for them, and concluded it was better to use a more restrictive option. Patients, however, preferred a less intrusive approach and cited rigid control as a means of escalating anger and aggression rather than a way to manage it (Hinsby & Baker, 2004).

Perhaps as a result of these issues studies have demonstrated the association between role conflict and burnout in psychiatric nursing staff (Melchior et al., 1997).

Gildberg *et al.* (2010) express concern at the fact that the majority of studies do not actively seek the opinions of patients, and instead base their knowledge purely on staff accounts. To the author's knowledge, there is a lack of research on community clients who are legally obliged to accept high levels of staff support. This group is likely to experience a similar professional-client relationship to those of ward staff and patients due to the similar nature of their role. In fact, the power struggle discussed with inpatients may even be emphasised as the relationship is one-to-one and therefore the supervisory aspects of the role are likely to be more obvious. The staff member is also within the client's home environment, which may be perceived as more intrusive for clients than occupying a shared ward.

The challenges outlined here have obvious consequences for the rehabilitative merit of a community-based rehabilitation model. A neglected question remains of how service-users with LD and forensic needs actually *experience* the community care model.

1.6 The experience of service users

1.6.1 Lived experience

Community-based care might logically be expected to reduce social isolation and we could attempt to demonstrate this with objective measures. What we will not know is if this intervention actually results in the client *perceiving themselves* as less isolated. We need to have access to the client's personal account for these kinds of questions to be answered.

There is agreement that subjective assessment, as well as objective measurement, is needed in order to appropriately measure complex concepts such as quality of life (Felce, 1997). Cummins and Lau (2003) comment that partially subjective experiences, such as 'integration', are often inappropriately gauged using only concrete measures, for example the number of community facilities in the area or the number of visits the individual makes to the shops. This can result in outcomes which focus too heavily on physical integration ignoring social and psychological aspects of integration, or sense of belonging (Cummins & Lau, 2003). Further, objective measures may not correlate well with subjective accounts (e.g. Aubry & Myner, 1996; Prince & Prince, 2002) perhaps because they do not incorporate the role of beliefs and personal meaning.

Many authors have begun to see the value of aiding natural 'bottom-up' desistance processes, as well as providing more 'top-down' rehabilitation, that is, listening to the client's views of what they feel would improve their chances of desisting rather than simply applying a generic approach to treatment (Maruna & LeBel, 2010). Farrall (2002) also emphasised the importance of the subjective views of offenders on their life changes. This is due to the fact that it was not the changes themselves (e.g. acquiring employment) which seemed to reduce recidivism but the meaning that was associated with these changes. Maruna (2001) refers to this in his work also, emphasising that changes in life circumstances were important as they allowed the individual to develop a new self-identity or narrative. It was this change in self-perception that seemed to aid long-term desistance.

Aside from finding out if interventions subjectively deliver what they set out to, there is also the question of *why* and *how* certain interventions work which can emerge via qualitative methods. Lewis (1990) points out that, although individual treatment may have a large effect in the limited world of inpatient wards, now that

community care prevails we should draw our attention away 'from programmes to lives' (p.923). He argues that research is needed not looking at whether certain interventions, such as intensive support, work or not but *why* they work (or don't work), and what types of clients benefit most. Accessing service user accounts seems to be one worthwhile means of answering these questions.

1.6.2 Partners in care

The Scottish government has pushed the agenda of service users becoming active participants in directing and developing the services they are part of (Scottish Executive, 2000b; Scottish Executive, 2001a).

To achieve these aims there has to be a culture change in the way the service interacts with the people it serves and the way services are delivered. It is no longer good enough to simply do things *to* people; a modern healthcare service must do things *with* the people it serves. What we are trying to achieve:

- A service where people are respected, treated as individuals and **involved in their own care.**
- A service where individuals, groups and communities are involved in improving the quality of care, in **influencing priorities and in planning services.**
- A service designed **for and involving users.** (Scottish Executive, 2001a,p.2; emphasis added)

Recognition is spreading that it is of even more importance to seek the views of vulnerable or legally restricted groups. For example research with service users has been carried out with mental health populations in prison (Sainsbury Centre for Mental Health, 2008), and more generally within forensic mental health services (Faulkner & Morris, 2003).The doubly vulnerable group of people with LD and forensic needs are, arguably, the people most likely to be restricted in their choices and the least likely to have a chance to voice opinions on their care.

Although the theories and policies discussed emphasise listening to the 'voice' of the service users, it is not clear that any service-user movement was responsible for driving the community care model. It is noteworthy that, when consulted, service users did not seem to favour the idea of community orders.

Generally, people were concerned about how [community-based] orders would work in practice with some people feeling that they might be stigmatising. Comments included: *"either people need to be in hospital or they don't, and if they don't they should not be subject to compulsion"*. (Scottish Executive, 2001b, p.7)

It also seemed from service-user comments that their sense of control did not stem from their environment, but was mediated by other factors.

Many service users said that they felt that they were powerless both in the community and in hospital. This was mainly because of problems in getting information about their rights and also because of the attitudes of professionals. (Scottish Executive, 2001b, p.4)

It seems, then, that the voice of this group has been neglected in the formation of these services and it is therefore even more important that their views are sought about how services could be shaped or changed.

More and more studies, however, are recognizing the value of qualitatively designed studies gauging service users' views on the services we construct and offer.

[...] we would like to emphasise the value of speaking with (service) users. Much of the 'evidence base' on which services are planned is quantitative data that can obscure and ignore many issues for service users. (Yacoub & Hall, 2008, p.11)

Participants in the current study are one of the most important stake-holders in the future of forensic care and have the potential to provide valuable input into service development.

Additionally, research into factors affecting general patient engagement indicates that when patients feel their views are being taken into account it results in increased treatment adherence, better self-management and promotes a more positive service user-provider relationship (O'Brien et al., 2008; Stewart, 1995). Studies within a mainstream forensic context also demonstrate the benefits of shared decision making and joint goal-setting with clients, including lower reoffending rates (McNeill and Whyte, 2007; Trotter, 2006). This suggests that incorporating patient views would not only be ethical, and in line with government policy, but might also aid risk management and reduce recidivism.

1.7 Summary and rationale

Rehabilitation for those who offend has evolved significantly in the last 40 years and has begun to broaden beyond individual intervention to the settings in which this takes place. The new MHA 2003 provides a framework for community rehabilitation, which has now become an option for many people with LD and forensic needs who would previously have been hospitalised. The advantages community living offers however, in terms of both increasing quality of life and decreasing risk, may not be as easily accessible to this group due to the legal framework around the individual and the very deficits the model hopes to address.

There is a need to explore the subjective experiences of service users in order to discover whether or not this model delivers the benefits, in terms of reducing dynamic risk, that it seems to offer in theory. It is also an opportunity to give a voice to this potentially vulnerable group in order to understand and evolve services, and promote a culture of partnership and shared goals.

2 Methodology

2.1 Design

2.1.1 Qualitative approaches

Justifying the use of qualitative methodology can be difficult in the current climate of evidence-based practice in health research. What is often meant by 'evidence' are large Randomised-Controlled Trials (RCTs), currently the gold standard in health research (SIGN, 1999). This means that 'evidence' often refers to large-scale numerical outcomes which aim to reach a clear answer via the presence or absence of statistical significance.

Qualitative studies, however, still have much to contribute to the evaluation of appropriateness of health care, that is, maximising the possibility that this care will benefit the intended recipients, and that this benefit is balanced with the overall cost (Grypdonck, 2006). Qualitative methods achieve this through making transparent the reasons behind the links thrown up in quantitative studies, and illuminating the 'why' (Grypdonck, 2006). Quantitative findings alone may overlook the possible complexity of a causal link risking a broad or unfocused intervention.

The type of methods applied should therefore reflect the nature of the question being asked (Remenyi & Williams, 1996). The current popularity of quantitative research may therefore be explained by the fact that the types of questions being asked in health-related enquiries are those best answered by hypothetico-deductive methods (e.g. *Does this intervention work? Which intervention benefits the most people?*). Many of these studies are carried out in an attempt to measure efficiency and reduce cost for the NHS; a necessary function in deciding which interventions to invest in.

Of course, qualitative research can become too narrow to be clinically useful, as there is too much emphasis on individual responses making it difficult to

generalise findings. In this case quantitative research is absolutely necessary to investigate which of the factors raised by participants can make a difference. This again highlights the need for a combination of approaches.

It seems that the types of questions being asked in healthcare are broadening, causing an increasing interest in qualitative approaches. Government policy has made a huge shift towards more service-user involvement in the development of services publishing various documents to this effect (Our National Health: a plan for action, a plan for change (Scottish Executive, 2000b); Patient Focus and Public Involvement (Scottish Executive, 2001a). Rather than simply asking '*Do services produce the anticipated outcomes?*', there are now additional questions of '*How do patients experience these services?*' and '*How do service-users want to see services change?*'. Qualitative methods are likely to contribute more and more as services become more patient-driven and we move from a compliance to a concordance model of care (Horne *et al.*, 2005).

2.1.2 Use of qualitative methods in the current study

As discussed, it is important that the methodology fits the question being asked. To the author's knowledge there have not been any other studies looking at LD service users' experience of community rehabilitation making the current study an exploratory investigation, without clear expected outcomes. The exploratory nature of this study means that a qualitative approach is more suitable. In addition, as the study is interested in the experiences and attached meaning for individual service-users, it is best answered via open-ended, participant-driven responses.

Quantitative studies tend to hold a positivist position in that they seek to discover patterns, facts, or truths about the world. It is not expected that the current research will result in factual outcomes as such, but will uncover the subjective opinions of those with lived experience of the topic. This fits with the underlying interpretivist philosophy of qualitative research which posits that

'truth' is relative to the individual and their context (King & Horrocks, 2010). Although there may be patterns across participant accounts, and therefore room for a broader interpretation, qualitative research remains an exercise of finding out what a number of people, subjectively, think about something.

From a practical perspective, if we want to work towards a more integrative approach to service design and delivery, a positive first step is asking for and listening to the views of clients. More and more studies are recognizing the value of qualitative designed studies in gauging users' views on the services we construct and offer (e.g. Yacoub & Hall, 2008).

2.1.3 Types of qualitative methodology

A number of different types of qualitative methodologies are available to the modern researcher. Those currently applied most often in health-based research are phenomenological methods, discourse analysis, and grounded theory (Starks & Trinidad, 2007). These methods may look similar in process, for example all use semi-structured interviews, line-by-line analysis, production of higher order and lower order themes, but they emanate from very different theoretical standpoints and their aims therefore diverge significantly (King & Horrocks, 2010). Grounded theory aims to develop a workable theory of a social process, discourse analysis looks at the use of language and narrative in the construction of meaning, and phenomenological analysis seeks to emphasise participants' experience of a certain phenomena (Starks & Trinidad, 2007).

A phenomenological approach was favoured in the current study as the main aim was to provide clarity on the viewpoints of the participants, giving voice to the experiences of a potentially vulnerable and marginalised group. It did not hope to discover an underlying social reality, rather to seek out the viewpoint of participants *because* they are subjective and biased. It is their *perceived* reality this approach hopes to explore.

Phenomenological analysis advocates a smaller number of transcripts analysed in more detail and so suited the constraints of the current project. There were a number of limitations on the study in terms of time and scope therefore it was necessary to be realistic and pragmatic with sampling. The available participant pool was small to begin with and the individuals concerned constitute a difficult-to-reach group for a number of reasons including communication difficulties; ethical issues relating to vulnerability and confidentiality; and access being subject to a number of gatekeepers due to the legal framework around them.

A number of phenomenological methodologies exist including descriptive empirical, heuristic, life-world, and hermeneutics (Wertz, 2005). Interpretative Phenomenological Analysis (IPA) belongs to the latter group and is a recently developed theory which allows phenomenological analysis to go further than it would traditionally. Rather than just describing participant experiences, it seeks to understand these in the wider theoretical perspective, converging more with the aims of grounded theory but stopping short of constructing a model or theory.

The choice of one approach over the others is not to say the remainder are ignored. There is a significant overlap between different qualitative approaches. IPA offers an attractive flexibility which allows for elements of theory development (through placing participants' views in an empirical context) and constructivism (through consideration of the use of language and non-verbal cues during interview and observations) whilst centralising the story of the individual. For any researcher, and especially a novice, this all incorporating approach is a desirable option.

2.2 Interpretative Phenomenological Analysis (IPA)

IPA was devised by Jonathon Smith and colleagues (e.g. Smith *et al.*, 2009). It provides a means of keeping the phenomenological principle of immersing oneself in the participant's 'lived experience' but going further than more traditional descriptive approaches by interpreting this account. The method therefore becomes two-fold, 'giving voice' to the participants and 'making sense' of their experiences in context (Larkin *et al.*, 2006).

As in all qualitative research, IPA attempts to work inductively, without a clear testable theory. It tries to do this in an entirely 'bottom up' way so that all information gathered is coming straight from the participants, with no agenda set by the researcher (Reid *et al.*, 2005). From this idiographic perspective participants are considered as the expert of their own world, in that they know most about their own experiences, thoughts, and interpretations.

IPA has been considered useful in the field of social sciences as it acknowledges the researcher's natural tendency to shape and interpret the data. This is seen as unavoidable and is openly discussed and considered as part of the analysis (Smith *et al.*, 2009). The analysis in IPA is thus based on two layers of interpretation, referred to by Smith and colleagues as a 'double hermeneutic', which means the data effectively passes through two filters.

...the researcher is trying to make sense of the participants trying to make sense of their world. (Smith & Osborn, 2003, p.51)

IPA is growing in popularity and has been used to explore, for example, the contribution of spirituality to the process of bereavement, the presence or absence of various health behaviours and participant experiences of health problems such as dementia and addictions (see Reid *et al.*, 2005 for a summary). IPA has also tried to re-emphasise the value of the single case study in understanding subjective experience, such as emotionality (Eatough & Smith, 2006). More recently IPA has been used successfully in a number of studies

carried out with participants with LD to explore a wide range of topics including self-harm, the meaning of employment, and trauma (Brown & Beail, 2009; Jahoda *et al.*, 2008; Mitchell *et al.*, 2005).

2.2.1 Theoretical underpinnings of IPA

IPA has its roots in the writings of philosophers Martin Heidegger and Edmund Husserl who provided the foundation of modern hermeneutic approaches (Smith, *et al.*, 2009). Husserl criticised the positivist views prevalent in the field of science pointing out that the 'facts' and 'certainties' mankind claim to have found are learnt through our own consciousness and are therefore inevitably perceived through the sheen of our own preconceived views and values. He suggested that in fact what we perceive as 'reality' is more accurately understood as what the majority of people think, the norm, rather than any hard and fast 'facts' about the world (Larkin *et al.*, 2006). This is reminiscent of the sentiments of Thomas Kuhn, who commented on the fact that all interpretation of scientific discovery was inevitably constrained by whatever scientific paradigm was operating in society at that time (Kuhn, 1962). Similarly Heidegger suggested that the person is always and irretrievably a 'person in context', with our point of view consistently tainted by our own self-identity (Blattner, 2006).

These ideas led onto the development of the interpretivist approaches present today in qualitative thinking which are at the core of IPA.

2.2.2 Principles of IPA

IPA strives to be idiographic, both in terms of focusing on the individual and on a specific topic area. Although emphasis is on expressing the 'voice' of the participant, this is only the first order analysis, and half of what the method strives to do. Unlike other forms of phenomenology, which merely present participant views in a descriptive way, IPA recognises the ability of the researcher with their background in social sciences and knowledge of the

literature to go further and interpret these findings in context. Again, similar to the process of psychological formulation which asks 'why this person, with this difficulty, at this time?' (Johnstone & Dallos, 2006), the data is not just a narrative but is viewed in light of the social, cultural and theoretical background which is always present around the individual (Larkin *et al.*, 2006).

There is a recognition that although themes will be based on the individual, the account can never be truly first person. It will always be a third person telling of the story as it comes via the researcher's interpretation (Larkin *et al.*, 2006). Therefore, on approaching a certain subject there must be an awareness of the questions being asked and the method of enquiry so that, as far as possible, the relationship being looked at is given the chance to show itself as it *truly* is (Larkin *et al.*, 2006). It is important to remember that IPA is always trying to observe a relationship, that is, how this person relates to or understands X, rather than trying to discover X itself, which is arguably not a tangible, discoverable thing in any case.

[IPA] attempts to explore personal experience and is concerned with a person's personal perception or account of an object or event, as opposed to an attempt to produce an objective statement of the object or event itself. (Smith & Osborn, 2003, p.51)

Realising the diversity of researchers' backgrounds, and resulting assumptions, there is a lot of room in how a participant's account can be interpreted. This flexibility is seen as an advantage but it is important that interpretations stay central to the person and the issue being discussed and remain grounded in their context. Previous research can be drawn upon, as well as psychological theory and clinical experience, as long as this can be kept directly related to the individual and the specific line of enquiry. This is sometimes referred to as 'epistemological openness' (Larkin *et al.*, 2006). The authors comment that it is important to note the researcher's framework, and this must be viewed objectively throughout. After all, the researcher, in the political and social

context of the time, decides what to focus on as 'fact' (effectively 'real-ising' these aspects) and which areas to question or reinterpret (in turn 'relativising' these) (Nightingale & Cromby, 1999, p.8).

The final stage of the analysis is a review of the interpretation. The researcher, recognising their tendency to interpret data in a certain light, considers the interpretation with a more critical eye and revises it accordingly. This completes the 'hermeneutic circle' (Smith & Osborn, 2003).

Empathy and flexibility are considered vital aspects for the IPA researcher. The ability to empathise helps us to experience and understand the perspective of the individuals so that we can document and consider *their* views as much as possible (Larkin *et al.*, 2006). Flexibility is also crucial; researchers must be able to adjust their responses and ideas according to what they hear. There is a risk that researchers can take up a rigid position of assuming to know the 'facts' of the situation, interpreting what is said in this light (Larkin *et al.*, 2006). The tendency to do this is natural and recognised and must therefore be kept in check during both the formation and execution of the study.

2.2.3 Translating IPA theory into practice

Knowledge of the underpinnings and principles of IPA is useful. It is important, however, that these can be translated into the practical execution of the research by directing the design, sampling, method of data collection, and analysis of the data.

2.2.3.1 Sampling

IPA methodology recommends that detailed analysis is carried out with a small number of participants (Larkin *et al.*, 2006). Smith & Osborn (2003) discuss sample size but conclude that a clear guideline cannot be specified.

There is no right answer to the question of sample size. It is partly dependent on several factors: the degree of commitment to the case study level of analysis and reporting, the richness of the individual cases, and the constraints one is operating under. For example, IPA studies have been published with samples of one, four, nine and fifteen. (Smith & Osborn, 2003, p.54)

Homogenous samples are suggested as numbers will inevitably be too small to generalise and it is therefore less important to have a randomised or representative sample. Purposive sampling is favoured in order to find a smaller population to whom the questions are more pertinent (Smith *et al.*, 2009). If the population being looked at is small to begin with then sampling will be predetermined, if not the population should be narrowed using appropriate characteristics or demographics. It is still possible to generalise findings within the context of the existing evidence base drawing conclusions about which groups the findings may be applicable to; this is referred to as theoretical generalisation (Smith *et al.*, 2009).

2.2.3.2 Data collection

IPA is concerned with seeing the world from the perspective of the participant on a broad topic. For this reason semi-structured interviews are considered the most appropriate form of data collection (Smith *et al.*, 2009). Use of open-ended questions allows the participant to steer the conversation towards topics that are relevant for them. Smith *et al.* (2009) provide guidance on the types of prompts which should be used, and the three appropriate situations in which to use them: to probe for further details, to clarify what the participant is saying, or to bring a part of the participant's account to completion (e.g. '*what happened after that?*').

2.2.3.3 Analysis

IPA looks to both understand the person's perspective and to critically evaluate this. This involves reading beyond the words themselves and hoping to reach a deeper meaning of what is being said (or not said). This leads to a further

analysis of the meaning of their narrative in the context of what we know about this person, their social and cultural context, and current psychological theory. The interpretation is therefore both 'empathic' and 'questioning' (Smith & Osborn, 2003, p. 51). For example, inferences can be drawn from the person choosing to answer questions in a certain way, focusing on one aspect and not another, appearing to be withholding, or emphasising or repeating certain aspects of his or her experience (Smith & Osborn, 2003). What the individuals are saying is thus assumed to be linked with an underlying emotional state, their core values and assumptions, and the context in which they live.

IPA intends to provide a set of guidelines for analysis, rather than a rigid set of rules (Larkin *et al.*, 2006). It is viewed as more of a theoretical standing than a practical guide, hence the exact coding method and theme extraction are not consistently described, however, guidance does exist. The following process is the amalgamation of descriptions of IPA analysis from Smith (2007) and Smith *et al.* (2009).

After fully transcribing the data researchers should familiarise themselves fully with the recording by reading and re-reading. This will allow them to notice verbal cues, repeated use of words and so on. Comments are then made in the margin and these take the following forms as they evolve: descriptive comments, linguistic comments, conceptual comments (beginning to interpret) and deconstruction (re-interpreting, looking for other possible meanings).

Following this the researcher identifies emerging themes. These should not be too general, so the complexity of the material is maintained, and convergence and divergence within participant accounts should be noted. The interpretation of the data then begins with the researcher beginning to consider what these themes might mean in the context for participants.

The knowledge of themes derived from the first participant is 'bracketed' as much as possible during the analysis of the next participant's transcript. This is similar to the way in which the researcher's own pre-existing knowledge of clinical practice or theory must be bracketed during initial analysis of transcripts to avoid influencing the themes identified. The data can then be looked at in the wider context of other participants' data as well as the researcher's relevant knowledge of the literature. The aim is to put the participant's ideas in context and, hopefully, yield a more interpretative account. Findings are then reflected on and reviewed with supervision, collaboration, and audit used as validity checks and to separate the voice of the researcher from that of the participant.

2.2.3.4 Quality assurance

Inter-rater reliability is often used in qualitative methodology as a check on the quality of the data. This involves a second researcher coding the data and developing themes on the same material. Themes can then be compared for consistency of interpretation, even reaching a numerical value of the extent to which the accounts agree (Armstrong *et al.*, 1997). This assumes however that there is a *right* interpretation of the data, contradictory to the principles of phenomenology. Of course there is still a need to provide checks on quality, and Smith *et al.* (2009) suggest that the ability to audit the process may provide an alternative. Audit can in one sense mean providing a tangible paperwork trail to trace every stage of the research process. This is an important part of quality assurance which is discussed later within the methodology. Audit can also be applied at a more detailed level in which a second researcher looks at the coded transcripts and resulting themes not with the intention of coding the data themselves but to check the analysis is rigorous. Even if the themes are not necessarily those the second researcher would have deduced, due to his or her personal context and perspective, they can confirm that the analysis is transparent and coherent.

Inevitably with the flexibility this method offers comes a loosening of both its theoretical standing and the guidelines for its practical application. Similarly with the relatively recent development of the approach comes the advantage of fresh, novel ideation, and the disadvantage of less experience of its application. These are recognised downsides of the use of IPA and illustrate a need to follow the methodology as rigidly as possible and ensure auditability throughout.

2.2.3.5 Transparency of the researcher's perspective

Part of the process of IPA involves making the perspective of the researcher transparent throughout analysis. It is important therefore to note my own personal and professional motivations for conducting this research.

My experiences in my alternate role as a clinician have heavily influenced my choice of research area. I have worked with a number of men with LD and forensic needs who are subject to legal orders. Although the support staff in this field are extremely committed they face a very difficult task. The sentiments behind community rehabilitation are positive and rights-driven, however, within my clinical work I have found that the restrictions clients are subject to and the interpersonal tensions with staff members means the model seems to create as many problems as it solves. There seems to be a clear conflict between the staff role of supporting the client and their role in managing risk which remains unaddressed.

Anecdotally, it appears that these issues add to the difficulty in moving clients on. Frequently these individuals will either continue to present risk management issues (which are unlikely to alleviate in many cases) or display a level of vulnerability which maintains their dependency on support. It is often unclear, to others and to the clients themselves, what level of staff support they can expect to move onto, and in what time frame. Many clients seem to expect complete independence following a period of close supervision, however, their

level of risk, and/or indeed learning disability, might mean this is unlikely to ever be possible. Should someone with LD not be permitted the choice of a finite prison sentence and a return to the community without significant follow-up (as their non-disabled counterparts would receive)?

My experience is likely to be skewed by having had contact with many of those clients who do not cope well within this model, although I have witnessed some clients move forward with success. I do feel very passionately about this client group as they are, in general, so shunned and misunderstood by society, however, I don't want to use my voice to say what I think service users want and feel as I think this has been the error from the start. Part of my motivation for this study was to look more objectively at the accounts of service users to obtain the beginnings of a clear evidence base.

2.3 Procedure

2.3.1 Participants

Ten participants, all male, were recruited from two health boards in Scotland. All met the inclusion criteria, but not the exclusion criteria, as outlined below.

2.3.1.1 Inclusion and exclusion criteria

The inclusion criteria outlined that all participants should be adults (16 years or over) with a diagnosis of LD. Participants also needed to have a forensic history, defined as a history of offending or being considered high risk of offending.

They needed to be subject to a legal order obligating them to accept high levels of staff support, due to the level of risk they presented. The type of order participants were subject to could be one of the following, dependent on their route through the criminal justice system: Compulsion Order (CO), Compulsory Treatment Order (CTO), or Welfare Guardianship order (GO). The participants

had to be deemed able to give informed consent to participate in the study, as judged by their Responsible Medical Officer (RMO).

The last aspect of the inclusion criteria was that participants needed sufficient receptive and expressive language ability to take part in a semi-structured interview, even if additional support by the researcher would be required. This was judged by a member of the clinical team who had sufficient knowledge of the individual. If there was uncertainty around the expressive and receptive language ability of a particular participant, clinicians working with these individuals were asked to refer to criteria from the Adaptive Behaviour Assessment System (ABAS). If the participant was considered to fulfil higher level communication criteria on this assessment (e.g. *'talk to others about sports, family, group activity, etc'* and *'use complex sentences containing 'because' 'but' etc'*) they were considered to meet the inclusion criteria (see figure 5).

Participants must:

- Be considered an adult (aged 16 years or over)
- Have a diagnosed LD
- Have a history of offending or be considered at high risk of offending
- Be subject to a legal order, which means they are obliged to accept high levels of staff support
- Be able to give informed consent to participate
- Be gauged to have sufficient expressive language to take part in an interview

Figure 5 Inclusion criteria for the current study

Participants would be excluded from the study if they were unable to concentrate for more than a short period of time. This would need to be extreme as the methodology allowed for both short interviews and, where necessary, interviews carried out over two sessions. Further exclusion criteria specified that participants would not be asked to take part if they were currently experiencing mental ill health to the extent that it would interfere with their participation, or that participation may further exacerbate the condition (e.g. severe depression or a current psychotic episode). These issues were explored with the RMO or other relevant members of the clinical team. Lastly, there was a flexible exclusion category to capture any other reason for non-participation put forward by the RMO or other members of the clinical team. Importantly, reasons in these categories would be discussed and, if these difficulties were insurmountable, recorded to avoid unnecessary exclusion (see figure 6).

Participants would be excluded if:

- Unable to concentrate for more than a very short period
- Currently experiencing serious mental ill health
- There were any other issues which the clinical team felt made the individual unsuitable for the study (*although this would be carefully considered first*)

Figure 6 Exclusion criteria for the current study

Only one participant who was approached declined participation. He was not asked to state a reason for this and did not give one.

2.3.1.2 Participant characteristics

Autobiographical details for participants are presented for the group rather than specified for each individual in order to retain anonymity to as high a degree as possible. Participants were all males aged between 23 years and 49 years; intellectual ability fell within the mild to moderate LD range. Six participants were subject to a community-based CTO; three were subject to a GO; and one was subject to a CO. Time on their community-based order ranged from one to fifteen years. The principle reason for implementation of the community order was sexual offending or sexually inappropriate behaviour, as was the case for eight participants. For one further participant serious assaults and violent behaviour were the reason for the order and in the final participant, threatening behaviour (see figure 7 for a summary).

Sex:	All male
Age:	23 - 49 years
Level of LD:	Significant learning disability range (previously mild-moderate range)
Type of order:	CTO (6/10) GO (3/10) CO (1/10)
Time on order:	1 - 15 years.
Previous living arrangements:	secure hospital (8/10) hospital house (1/10) living with family in the community (1/10)
Nature of index offence/behaviour:	sexual offending or sexually inappropriate behaviour (8/10) serious assault (1/10) threatening behaviour (1/10)

Figure 7 Summary of participant characteristics

The specific home environments of participants varied slightly but they all lived in their own tenancy and received intensive staff support as part of their legal order's requirements. Living arrangements are more fully described below.

2.3.1.3 Services from which the current participants are drawn

The participants in the current study are drawn from two health boards in Scotland (Health Board 1, Health Board 2), supported by four care providers in total. Care Providers A and B provide support to service users in Health Board

1; Care Providers C and D in Health Board 2. All care providers delivered intensive staff support to clients on community-based legal orders, however, the provision of this care can vary.

In Health Board 1, Care provider A is a private organisation employed by the council to support individuals in their own private residences. Care Provider B is the council owned support service supporting individuals within their own private tenancies. These organisations also have several 'core' houses across the Health Board area. These 'core' houses serve as a base where staff can withdraw when the service-user has free time or to sleep in when sleepovers in the client's home are being gradually withdrawn. It is also intended as a social area where service users from the area can congregate.

The set-up of services within Health Board 2 is slightly different. Both the care providers are private organisations employed by the council. Care Provider C provides support to people either within small shared residences of three to five people (with two to three staff present) or within housing blocks of service users which have been equipped with smart technology in order to reduce staff requirements. Within these blocks, one flat serves as a staff base and from there service users can be monitored by means of alarmed doors, cameras in the stairwell and outside the doors, and sensors that detect when a service user stands at the windows for a prolonged period. Other adjustments, such as automated blinds which are programmed to open and close at certain times, are employed.

Care Provider D has a similar set up, using residential blocks within a small area. The staff base is slightly removed in this case, and is a few doors down from the others residences. Service users are again monitored using Smart technology similar to that outlined above.

2.4 Data collection

2.4.1 Development of the interview guide

The interview guide¹ was constructed following wide reading of IPA principles and the specific recommendations of Smith *et al.* (2009). They were reviewed in consultation with the project's academic supervisor who has extensive experience in the use of qualitative methods. Questions were as open-ended as possible in accordance with the principles of IPA. As the population under investigation has communication difficulties, however, a number of follow-up questions were also included, in case the participant was unclear about the meaning. An example of this is shown in figure 8.

¹ A copy of the interview guide is included in Appendix 1

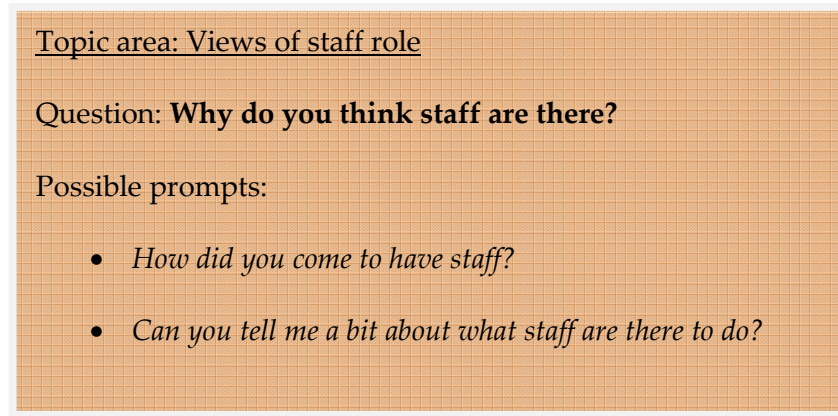


Figure 8 Example of questions and possible prompts included in the interview guide

Further prompts were used only as recommended in Smith *et al.* (2009).

2.4.2 Pilot phase

Below is an outline of the protocol for the study's data collection phase. This process was initially carried out with one pilot participant in order to raise any short-comings in the methodology. Following the pilot shadowing session and interview the methodology was reviewed but remained unchanged and therefore the process was repeated for all participants. As the methodology remained unchanged data from the pilot participant was included in the study.

2.4.3 Stage 1 (Initial approach)

The contact clinician in each health board drew up a list of clients who fulfilled the inclusion but not the exclusion criteria. These names were not given to the researcher at this stage, nor were any identifying details. Information about each potential participant was not passed on until that individual consented to meeting the researcher.

The RMO for each of these clients was approached to ensure the client was deemed able to consent to the study. In the case of one of the health-boards

(Health Board 1) the RMO was newly appointed and was not able to give a clear indication of all clients' ability to consent. In consultation with the clinical supervisor it was decided that the Mental Health Officers (MHOs) were the most appropriate alternative. To back-up the opinion of the MHOs, members of the multidisciplinary team were also asked if their opinions differed.

If the client was considered able to consent the RMO, or another clinician known to the client, approached the individual in the first instance to provide information about the study. At this point the RMO presented the client with the Participant Information Sheet (PIS)² and briefly explained the study. The client was then asked if he would be happy to be approached by the researcher. If the client did not give consent to being approached, the process ended for him at this point.

2.4.4 Stage 2 (Providing further information/seeking consent)

Details of the clients who agreed to be approached were given to the researcher. The researcher then contacted the client, or his staff team, and arranged a date to meet with him to explain the study further.

During this meeting the researcher took the client through the PIS in full. It was explained that, to take part, he would need to consent to the researcher accessing certain information from his medical notes (details of the type of legal order he is subject to, the length of time he has been subject to that order, any relevant risk management procedures). In addition it was explained that the support staff team would need to be informed that the researcher would be visiting and given some brief information about the study.

The researcher explained to the client that if he agreed to the study he was agreeing to meet on two occasions. On the first occasion the researcher would

² A copy of the PIS is included in Appendix 2

arrange to shadow the client in his own environment to allow the parties to become more comfortable with each other and so that the researcher could observe the client's daily activities and the support he received.

The second meeting would take place approximately 1 week after the first in at a convenient time and location for the client. The client's home was the first choice of venue, however, if this was not appropriate an alternative venue would be found.

Clients were allowed a period of one week to think about their decision and go over the information with whomever they chose. A few clients, who had already read through the PIS and had discussed this with others, were willing to sign the consent form³ at this point, and did so. They were reminded that even if they had consented to the study they were free to withdraw this consent at any time.

If the client agreed to take part a suitable time and date was arranged, in conjunction with support staff, for the shadowing session.

2.4.5 Stage 3 (shadowing session)

The researcher arrived at the participant's home at the date and time agreed. This initial visit took place in line with departmental guidance policy and with support staff present to overcome any potential risks. On arrival, the researcher offered to review the relevant section of the PIS with the client to ensure he understood what the study involved and had an opportunity to ask questions.

If the client was still willing to take part the researcher supported him to read through the consent form with support staff present. Once the researcher assessed that all aspects of the study had been understood by the client, and the client was satisfied with the information, he was asked to tick the relevant boxes and sign. A witness, usually a member of the support staff team, also signed the

³ A copy of the Consent Form is included in Appendix 3

form. The researcher reiterated that the client was free to stop the study at any point if he no longer wished to take part.

Clients were asked if they were comfortable with taking photographs of their environment. In line with risk management procedures it was explained that photographs of other people would require their explicit permission. Any taken without explicit permission would be immediately deleted from the camera. These photographs were for use as prompts during interview and were either destroyed or kept by the client thereafter. If the clients were happy with this they were given use of a digital camera for the duration of the shadowing visit. The photographs were instructed to be of anything in the environment the client deemed important.

Following this visit the researcher offered the client a chance to ask any questions before the researcher confirmed a time and venue for the follow-up interview.

2.4.6 Stage 4 (interview)

As the interview would take place without staff members present, prior to this visit the researcher familiarised themselves with any relevant risk management guidelines related to the client.

The researcher arrived at the client's home (or alternative agreed venue) on the day of interview. For personal safety the researcher had a personal alarm at hand throughout the interview, unless the accommodation had its own alarm system, in which case this was used instead. It was explained clearly to both the staff member and the client that the alarm was a precaution and would only be sounded if the researcher felt in danger.

The staff member accompanying the client was asked to remain at a sufficient distance to ensure privacy but close enough to respond to the alarm in the event it was activated.

The researcher then reviewed relevant sections of the PIS and the interview guide with the client. The researcher reiterated that the client was free to stop the study at any point for any reason, and could refuse to answer any questions he did not feel comfortable with.

The interview then began in accordance with the interview schedule and prompts; these were employed flexibly to allow the participant to direct the conversation. The photographs were used to open the conversation and to facilitate an initial descriptive discussion of the participant's home environment. Each interview lasted for a maximum of 90 minutes (timings varied depending on the client) and was recorded on a digital device.

Following the interview there was a short debriefing period where the client was asked how they found the discussion. They also had a chance to ask any questions. The researcher agreed that once all the information had been gathered for the study the client again would be contacted and offered feedback regarding the outcomes of the research (see figure 9 for a summary of this process in full).

The PIS, a hard copy of which was provided to the clients and their staff teams, also contained information for anyone wishing to submit a formal complaint about the conduct of the study.

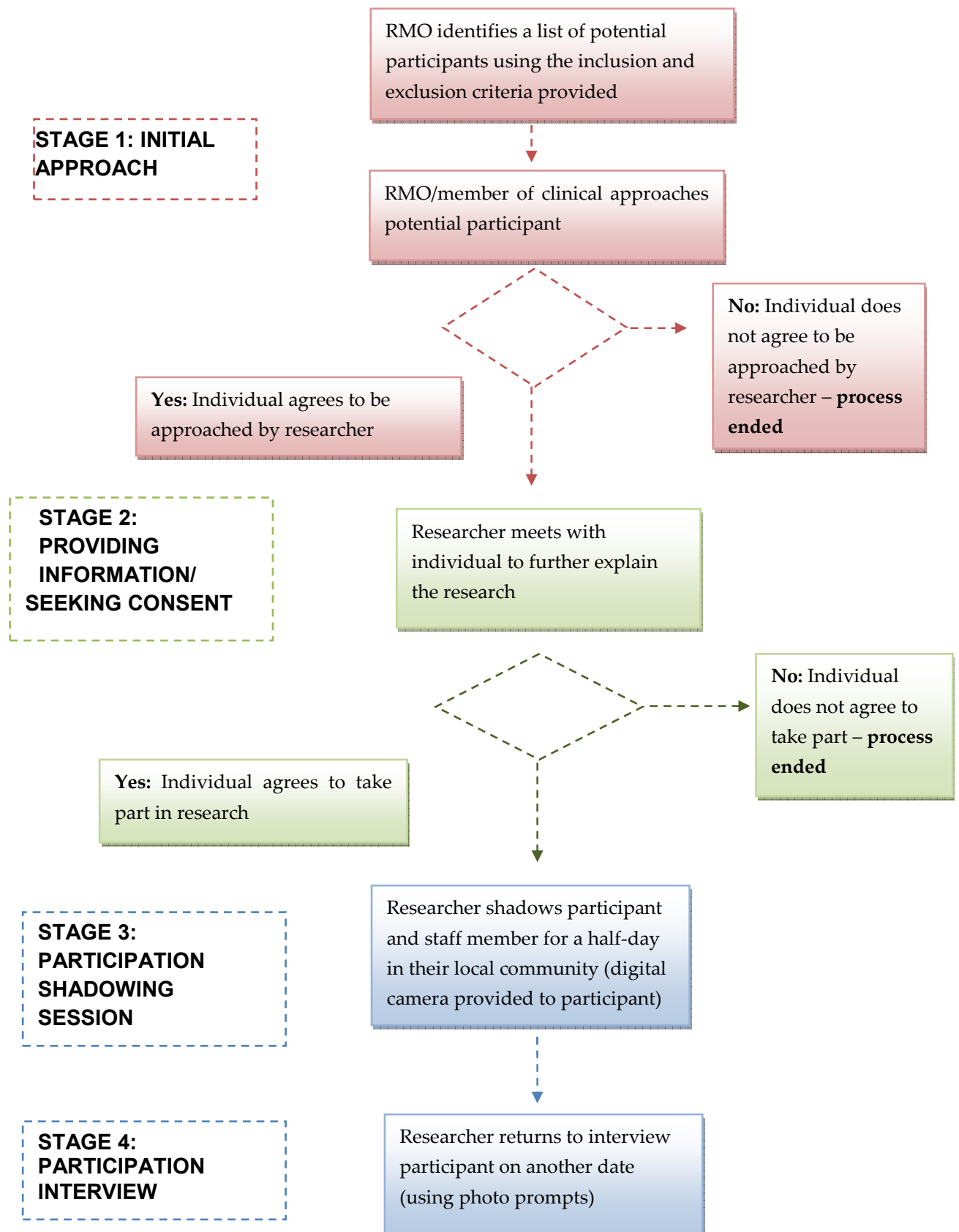


Figure 9 Flow chart of the data collection phase

2.5 Process of analysis

2.5.1 Transcription

The interviews were recorded using an Olympus DS-2400 Digital Voice Recorder and lasted between 25 minutes and 90 minutes. The digital recording was downloaded immediately when the researcher returned to the workplace. The recording was saved onto the researcher's password protected drive on a secure NHS computer. The interview was then transcribed using appropriate Olympus software. Following this the recording was deleted from the digital voice recorder.

As the analysis is concerned with semantics, transcribing is recommended to include all words spoken plus false starts, laughs, pauses, etc (Smith & Osborn, 2003). A slightly modified version of the coding system recommended by King & Horrocks (2010) was therefore used for all transcripts⁴.

If any verification of the words on the recording was needed this was done by the clinical supervisor. The data was then anonymised by removing the participants' names (which were replaced by a number) and removing any details which could be used to identify them. In the later stages of write-up further details were removed from any direct quotations in order to shield the identity of the patients from support staff or other professionals who may know them well (e.g. specific types of work placement, specific hobbies).

The researcher kept a list, again on a password protected drive on a secure NHS computer, of relevant participant details, for example age, sex, details of legal order. This was used to match these details to the anonymised participant number so this context could be included if relevant to the write-up. Again, if

⁴ A copy of this key is included in Appendix 4

the type of order or exact number of years the person was on the order was potentially identifiable information, this was masked in any verbal feedback or write-up of the study.

In line with NHS research policy the transcriptions will be kept securely for a period of 5 years before being destroyed.

2.5.2 Coding

Data was coded according to Smith *et al.*, (2009). Transcripts were read and re-read. The data was then transferred into a table with three columns, which allowed notations to be documented in one column, and emerging themes in the other (see figure 10). Initial notes were then made line by line in the second column noting aspects which were: frequently mentioned; appeared to evoke emotionality in the participant; relevant due to pauses or omissions; or interesting in terms of the individual's overall narrative. The researcher's own reflections on the data were also noted within this column, beginning the interpretation stage. Emergent themes were formed attempting to condense the data without losing the richness. Themes were given titles which attempted to maintain the voice of the participant, using dynamic phrases, (e.g. 'not knowing what will happen'), rather than restrictive categories (e.g. 'uncertainty').

Transcript	Notes	Emerging themes
<p>P: Well, it's ok to have staff because, em, the thing about staff is that they're there if you need them.</p> <p>I: Mmhmm.</p> <p>P: But if you didn't need them then there's nae point in them.</p> <p>I: And do you need them?</p> <p>P: Ah, I say "No" but I'd nae choice.</p> <p>I: Right.</p> <p>P: Ken what I mean? I had nae choice to either...well, I had this a couple a year ago, eh? Just, I told, I told [psychiatrist name] that I didn't want staff support at all. He says, "If you dunnae take that...then..." ,[laughs] I took, I took about a couple of weeks to think about it, eh? And I thought, see [name's] alright but he does'nae ken what he's talking about. So basically, ehm, I was saying, I was saying to him that I didn't need staff and he sorta said, "Well, if you dunnae keep staff you'll no be, you'll no be getting out so-</p>	<p><i>Feels he can get help from staff if they need it but seems to feel that otherwise they (appropriately) hang back and let him get on with things. Staff as an empowering device rather than something inflicted on him (feeling of internal control/empowerment attached to this)</i></p> <p><i>However, still does not see them as necessary</i></p> <p><i>Here in contradiction he talks about having no choice in whether or not to have staff. It seems to have been a choice between having staff and returning to the community or staying in hospital. He was however given that option and still saw it as his choice in the end.</i></p> <p><i>The tone of this P seems to be quite settled at the idea of staff – he is not indicating frustration or resentment despite feeling staff are unnecessary.</i></p>	<p>EMPOWERMENT/ Taking support when I need it</p> <p>Making my own choices</p> <p>LACK OF CONTROL</p> <p>Having to have staff</p> <p>(This contradiction between themes is coming out a lot in the data – is it a reflection of the general ambivalence Ps feel – they are free but they're not free, have choices, but within limits...)?</p>

Figure 10 An example of line by line coding

The researcher then looked across themes attempting to connect these to form higher-order themes through a process of abstraction, subsumption, and

polarisation. Themes and sub-themes were formed into a table illustrated with quotations. Once this was completed for one participant the researcher moved onto the next participant. Ideas from the first participant were bracketed as much as possible while the same process was followed for the second transcript. Once coding was complete for all ten transcripts themes were developed across participant accounts by looking for recurrent patterns. These categories were formed and reformed until they seemed to capture the data as a whole. Findings were then interpreted within the context of the researcher's knowledge and the empirical context.

Sections of two transcripts were given to the academic supervisor to verify themes were coherent and transparent, as a form of auditability.

2.5.3 Consideration of computer aided analysis

NVivo 9 (QSR International) is a software package designed to help with the qualitative data analysis. The decision not to use a software package like NVivo 9 was made for a number of reasons. Firstly, the advantages a software package can offer may not be as relevant to this particular study, for example it is particularly useful for managing data from a large amount of participants and the current study involves a smaller number of transcripts.

Some authors have also advised that there are disadvantages to the use of software programmes such as NVivo for those new to research. The novice researcher is advised to use software packages with caution as the analysis can become driven by the programme rather than the chosen methodology (Barbour, 2008). IPA writers do not seem to advocate software packages particularly and warn that it can interfere with looking at the overview of the data (Smith *et al.*, 2009). Like other qualitative methods, IPA makes frequent reference to 'staying close to the material' (Smith *et al.*, 2009, p.7). It was feared

that some of the immersion in the data may be lost if computer analysis was applied.

2.6 Ethical issues

There were a number of ethical issues involved in the current study; it not only involved a vulnerable population but also explored the topic of their current care. Due to participants' high levels of supervision, the very topic being explored, it was impossible to ensure the kind of anonymity other research could offer. These issues were considered in-depth at the planning stage.

Due to the researcher's affiliation with both the University of Edinburgh, and the NHS, the study and all materials involved were subject to ethical review by both these institutions. Following amendments suggested by these bodies the study and all associated materials were passed by an NHS ethics panel and by the local NHS management⁵.

2.6.1 Gaining informed consent

One of the main issues when focusing a study on people with LD is informed consent. Government guidance emphasises consent as a process, rather than a single event, which may take time to establish (Department of Health, 2001b). It must be clear that the individual is:

- capable of taking that particular decision ('competent');
- acting voluntarily (not under pressure or duress); and
- provided with enough information to enable he or she to make the decision. (Department of Health, 2001b, p.3)

To confirm decision-making ability in the current study the RMO was asked to gauge the individual's ability to consent to a research study before initial

⁵ Documentation confirming this is included in Appendix 5

approach. Once it was established that the person was able to give consent to this type of study he was first approached by either the RMO or a member of his core clinical team rather than the researcher to avoid any perceived undue pressure to participate.

Studies involving people with LD do tend to show that these individuals can focus too heavily on pleasing the researcher and may not understand that they have the right to withdraw their participation (Goldsmith *et al.*, 2008). If the participant agreed to meet the researcher in the current study, this initial session was to provide information only, it was not taken as an indication they would be willing to participate. At this session the individual was given a full explanation of the study, both verbally and in written form. The PIS outlined all aspects of the study and clearly explained that:

- there was no expectation on them to take part;
- no pressure to take part would be applied by the researcher, any other professional, or members of their staff team; and
- their care would not be affected in any way if they choose not to take part.

The one week period following this session was intended to give the client time to consider and discuss participation with others so that their decision could be made in an informed way.

Before participation in the study was confirmed, participants had to sign a consent form. This required the individual to indicate their agreement with different parts of the study to ensure participants are clear on all components before signing at the end of the document. A witness was also asked to sign this document as verification that the participant understood and had consented freely.

Significant effort was put into making both the PIS and consent form accessible. It was initially developed in accordance with principles of accessible information suggested by CHANGE guidelines (2010) using appropriately simplified terms and supporting visuals. It was then reviewed by an NHS Speech and Language Therapist, working within a learning disability forensic service and changes were made in accordance with this.

The researcher then presented the documents on two occasions to a Patient Focus and Public Involvement (PFPI) group. This is a group of learning disabled inpatients who meet regularly to discuss service-related issues in one of the target NHS health-boards. Some members of this group had a forensic background and some did not. Feedback was taken from this group on the documents and also on more general issues of concern to these individuals when being asked to take part in research. For example, some individuals had concerns about their forensic pasts being raised as a discussion topic during interview. Specific reference to the fact that past offending would not be a topic of discussion was added to the PIS as a consequence.

It was agreed that if a potential participant indicated that he was willing to take part, but there were doubts about his ability to consent, the researcher would consult with the clinical supervisor or another senior colleague. This process was never required, however, possibly due to significant consultation with RMOs and MHOs prior to the individual being approached.

Scott *et al.* (2006) discuss the implications of 'consent' in the research domain as not just related to capacity but concerned with weighing benefit to the public against benefit to the individual. The authors emphasise the fact that the pendulum has swung much more in favour of the latter in recent years, reflected in data protection legislation and NHS governance policies. The pursuit of research that tended to seek knowledge for the sake of knowledge has no doubt

been part of the reason for this shift. The current study is framed within more practical concerns and will strive to benefit the participants themselves, as well as the wider pool they are drawn from, by feeding back their views to professionals and care providers. Feedback can and should help to shape the way in which staff support is delivered by emphasising both the positive and the negative features from a service user perspective.

2.6.2 Participants' ability to express their views

There is often a concern that people with a learning disability may not be able to take part in qualitative research as they will be unable to express verbal opinions adequately. Although this challenge deserves acknowledgement when conducting this type of research with groups who have expressive language difficulties, with the right modifications these challenges can be overcome.

The challenges faced by qualitative researchers doing research with this group, like the challenges faced by the individuals themselves, are as much a product of the interactions between them and the wider context as of any inherent impairment. (Nind, 2008, p.4)

In past studies a third person, such as a carer, has sometimes been asked to take part in the research to help the participant to express his or her views (Bogdon & Taylor, 1982). In the current study this was deemed inappropriate as a topic which could arise during interview was the care the participant receives from these very individuals. Consideration was given to having a neutral figure that was known to the participant, such as an advocate, present for the interviews. Previous research into these issues, however, has suggested that when other non-learning disabled attendants are present, interviewers tend to value their views above that of the client themselves (Bogdon & Taylor, 1982). This is despite the fact that carers do not consistently predict the views of their clients with accuracy (e.g. Harner and Heal, 1993).

There is a plethora of evidence available to suggest that people with LD can participate in semi-structured interviews on a range of topics including self-harm (Brown & Beail, 2009); sex life (Yacoub & Hall, 2008); stigma (Craig *et al.*, 2002) and mental health problems (Taggart *et al.*, 2009). Brown & Beail (2009) explicitly address and dismiss claims that this client group cannot participate in qualitative research.

Presumably the assumption is that, because of their limited vocabulary and expressive language skills, people with intellectual disabilities will not be able to provide the richness of data relevant to this research method. In this study, participants talked openly and added insight to our understanding of the situation. (p. 511)

Despite this, it is essential that steps are taken to reduce the potential barriers to communication. As the researcher had experience of working with this client group communication was used flexibly and language and phrasing were adapted appropriately during interview.

The methodology included meeting participants prior to interview for half a day's 'shadowing' so that:

- the participant felt more comfortable with the researcher before the interview took place;
- the researcher had some knowledge of the participant's environment/context which could be used to facilitate dialogue during the interview; and
- photographs could be taken of the participant's environment which were used as visual prompts during the interview.

A pilot interview was also conducted before beginning the study to allow the researcher to familiarise herself with the most beneficial interviewing techniques to use with this group.

The method of interviewing was able to be used flexibly if necessary (i.e. shorter interviews or two separate interviews) either due to the participant's levels of anxiety or due to concentration and attention difficulties. Although this proved unnecessary with any of the participants recruited, it was an option available to them.

Similarly, prior to the interview it was explained that if, at any time, the participant wanted a break or to discontinue the interview they could do so. The researcher was vigilant to signs of fatigue during interview and encouraged the participant to take a break or discontinue the interview if this was thought necessary.

2.6.3 Confidentiality

Anonymity and confidentiality were important considerations in this study for a number of reasons as outlined below.

- Participants were drawn from a very discrete population and were therefore already more likely to be more identifiable;
- Participants have forensic backgrounds. Privacy and confidentiality must, therefore, be balanced carefully with awareness of potential risk issues. Risk was most effectively managed by staff members being present during the information and shadowing sessions, and remaining accessible during participant interview. It was therefore necessary to make staff aware of the client's involvement in the study, compromising anonymity;
- Support staff work intensively with these clients. It is possible that certain details in the interview data, although anonymous to the general public, may still be identifiable to staff members who have worked with, or are familiar with, the client.

These issues were difficult to overcome, however, efforts were made to counter this where possible. Where anonymity could not be guaranteed the researcher made these limitations transparent to allow the individual to make the most informed decision possible about participation. For example, the client was made aware from the outset of the study that support staff would need to be aware of the researcher's visits, present during the shadowing episode, and given some information on the study, as these were necessary aspects of the process.

Efforts were made to maximise privacy during interview. Support staff were asked to leave enough distance so the participants could feel confident that their comments would not be overheard. Following transcription data was anonymised, and any specific details that may have been identifiable were extracted. All non-pertinent details from the interview data were removed, where possible, or altered to safeguard participants' identities.

2.6.4 Perceived impact of participation

It was acknowledged that the topic area of this investigation was a sensitive one, particularly in the light of the limits of participant anonymity as discussed above. In theory participants were being asked to comment on the experience of rehabilitation via staff support, that is the model of community care they received. In practice, however, they illustrated this with examples of the practices of individual staff members, some of whom were still a part of their team.

Before recruitment of participants began efforts were made to communicate the aims of the study to involved care provider organizations and individual members of staff. The purpose of this was to alleviate any concerns specific organizations may have harboured in relation to the discussion of practice methods as there was a risk this could filter down to staff and impact upon their treatment of clients. Letters were sent to seniors and managers of the care

provider organisations within the recruitment pool outlining the nature of the research and its aims and the reasons why staff opinions did not form part of the study⁶. PIS were also left at staff bases and staff members supporting individuals who were approached about participation were engaged in an active discussion, where possible, about the study and its aims.

2.6.5 Managing risk

Mental health professionals working with forensic clients can often become acclimatised to anti-social or threatening behaviour but it is important to keep in mind the risk issues (e.g. McIvor & Petch, 2006). This is not solely for researcher safety, it is also important to be mindful of how someone who is unfamiliar with risk protocols could place the client at risk, for example, if the researcher were to raise a topic or give a non-verbal cue which was a specific trigger for distress or anger. As the interview component of the study involved the researcher and participant being alone together it was important for the researcher to familiarise herself with the participant's risk management plan beforehand and to have a discussion with members of the staff team about possible risk factors.

An additional risk issue in this environment was disclosure. Disclosure here refers not only to the disclosure of further offences, or an intention to offend, but also to the disclosure of harm, or potential harm, to the participant by third parties. As the provision of care and support to these individuals was the topic under discussion it was reasonable to assume that neglect or abuse could be uncovered. The PIS explicitly stated that any disclosure of harm towards self or others would be reported and could not be kept confidential. This was also emphasised orally before the interview and a protocol was in place to address any such disclosures⁷.

⁶ A copy of this letter is included in Appendix 6

⁷ An amalgamation of these risk-related protocols is included in Appendix 7

2.6.6 Other psychological considerations

The topic under investigation can be, in the researcher's clinical experience, a very emotive one for participants and may also be intrinsically connected to other sensitive areas, such as previous offending behaviour. It was important to prepare a balanced response to manage the situation if a participant became distressed during the interview. Such a response would need to be appropriate but also maintain the researcher-participant boundaries. A guideline was therefore in place for use during interview⁸.

2.7 Quality assurance checks

Traditional methods of quality assurance used in quantitative methodology, for example objectivity, generalisability and randomised sampling, cannot be sensibly applied to qualitative methodology (Yardley, 2000). As with any type of research, however, qualitative projects must be subject to quality checks appropriate to the methodology.

There is already a healthy body of evidence in existence, stemming from both public bodies and qualitative researchers themselves, advising on quality assurance procedures in qualitative research. For example, the Critical Appraisal Skills Programme (CASP) is an organisation attached to the public health institute in England which provides advice and guidelines for evidence-based health research. CASP guidelines raise a number of helpful questions which provide a check on the credibility and rigour of a qualitative project (see figure 11).

⁸ A copy of this protocol extract is included in Appendix 8

- **Appropriate design:** Was the research design appropriate to address the aims of the research?
- **Sampling:** Was the recruitment strategy appropriate to the aims of the research?
- **Data collection:** Were the data collected in a way that addressed the research issue?
- **Reflexivity:** Has the relationship between researcher and participants been adequately considered?
- **Ethics:** Have ethical issues been taken into consideration?
- **Analysis:** Was the data analysis sufficiently rigorous?
- **Findings:** Is there a clear statement of findings?
- **Validity:** How valuable is the research?

Figure 11 CASP quality assurance guidelines for qualitative research projects

Smith *et al.* (2009) cite Yardley's work as a basis for quality checking. Yardley's criteria are similar to that of others in the field (e.g. Elliot *et al.*, 1999), however, she broadens the categories used and attempts to make them applicable to any qualitative research regardless of ideological background (Yardley, 2000). This is an important step as so many different types of methodologies fall under the umbrella of qualitative research and not all quality checks are appropriate to each. For example, triangulation methods may be less relevant for relativist-based methodologies where researchers would not expect to see a high level of inter-rater reliability and all perspectives are considered valid. The three broad categories Yardley recommends are: (i) sensitivity to context, (ii) commitment, rigour, transparency & coherence, and (iii) impact & importance.

2.7.1 Sensitivity to context

This refers to the empirical context, a solid grounding in the methodology of choice, a good background knowledge of the social and cultural influences on the study population, the context of the researcher, and the relationship between the researcher and the participant (gender, general status, status of researcher/participant, perceptions, roles; not *'why is the participant saying this?'* but *'why is the participant saying this to the researcher in this situation?'*).

As knowledge of the research context and underpinnings of the methodology in the current study have been covered in previous sections these will not be rehearsed. The participant's individual context was something the researcher strived to capture through multiple visits prior to the interview stage. During the shadowing episode the researcher made efforts to stay within the background so as to observe the natural interactions as much as possible (though it must be said that this was not always easy). Extensive field notes were made following each visit and photos were taken to capture the 'context'. Unless this was inappropriate, all parts of the study took place at the participants' homes to enable them to feel as comfortable and safe as possible. This also meant that the participants' 'context' surrounded them and remained the focus of any discussions, including the taped interview.

The relationship between the researcher and the participant was also considered. Some of the participants had been known to the researcher previously in her capacity as a clinician, an unavoidable difficulty in the small target population. In order to signal the fact that this was a different type of encounter the researcher made efforts to wear casual clothes, speak more openly about personal activities and home-life when asked, and to curtail any discussions emphasising referring to clinical role.

2.7.2 Commitment, Rigour, Transparency & Coherence

Yardley refers to the above as the basic principles that should be adhered to in all research. Commitment is emphasised as Yardley feels that '*prolonged engagement with the topic,(...) the development of competence and skill in the methods used, and immersion in the relevant data*' (2000, p.221) are essential. Prolonged engagement is also something that has been highlighted by other authors (e.g. Lincoln & Guba, 1985). Engagement with the topic in this context does not simply refer to the study exclusively, it also encompasses personal or professional affiliations with the topic (Yardley, 2000). The researcher has worked for four years as a clinician with an LD forensic client group, many of whom are subject to legal orders in the community. Working with clients and staff teams to aid successful rehabilitation of these individuals has been a large part of this role. The researcher is therefore committed to the client group and to working towards the improvement of this community care model.

Familiarisation with the methodology is also an important aspect within this category. The researcher has attempted to immerse herself in the methodology through extensive reading on IPA; consultation with the academic supervisor, who has published IPA studies in health research; attendance at IPA conferences and regular attendance at an IPA study group. The researcher sought advice from a prominent researcher in the field who had completed a number of qualitative studies with clients with LD. It was important to consider the fact that this client group has additional communication difficulties which may present a challenge to any methodology applied. For example increased prompts may be necessary to facilitate communication but this needs to be balanced with awareness of the acquiescent nature of an LD population. The clinical supervisor, with over a decade of experience with this client group, facilitated interview role-plays to anticipate the possible difficulties with any interview questions or prompts. The initial pilot interview served as a safeguard

for any methodological short-comings which could not have been predicted beforehand. It was also a chance for the researcher to familiarise herself, practically, with the appropriate balance between non-directive questioning and maintaining the focus of the interview.

Transparency alludes to the idea of auditability, meaning that a third party could repeat the processes carried out by the researcher and understand their interpretation, even if they would not come to the same interpretation themselves. The transparency of qualitative research can be more difficult as conclusions are integrally linked to the influence and interpretation of the researcher themselves. Keeping further aids, such as memos, which effectively serve as a reflective journal, and field notes, documenting thoughts following each encounter with a participant, can add lucidity to the links between each stage of the research (Holloway, 1997; Strauss, 1987). Both memos and field notes were recorded throughout the study and extracts from these are included in relevant parts of the results section.

The current project was subject to individual audit by the academic researcher on two transcripts and an audit trail was also kept throughout the study. An audit trail refers to all documentation involved in a research project, for example notes from discussions with colleagues, ethics approval documentation, annotated transcripts, drafts of reports. These are the documents that in theory would mean an individual could independently audit the pathway of a project and follow each step through to its conclusion (Smith *et al.*, 2009).

Triangulation of sources was also used in the current study. The interview is the main data source but this is enriched by the observations noted from the shadowing session, which provided a unique opportunity to observe the participants in their daily lives. Triangulation in this case is employed not as a method of checking the validity of the data, but as part of the process of data

'thickening', to ensure descriptions of the phenomena are as full as possible (Patton, 1999). For example, if what the participants said did not match with the noted observations during shadowing, this was not taken to invalidate their statements, but the apparent incongruity was of interest. It may suggest an ambivalence on the part of the participant, or may cause the researcher to reassess any assumptions made during her observations.

2.7.3 Impact & Importance

This refers to the practical use of the piece of research in widening understanding of a topic or prompting changes to current practice. The current research is not designed to be for interest sake only. It is hoped that it could help vary the established practices with this client group through dissemination of the findings to support staff and other multi-disciplinary professionals. Yardley (2000) highlights the fact that because qualitative methods emphasise people in their own context, they can prove more efficacious as the transfer from research to practical application lessens. In addition to service development it is hoped the dissemination of this research to the participants themselves will provide a greater sense of advocacy and self-efficacy, in understanding that their voice can have an impact.

3 Results

This chapter outlines the themes which emerged from the data following comparison of individual accounts. Superordinate themes, and their subordinate branches, are presented here, using verbatim extracts to illustrate each. Where there is a move from description to interpretation, attempts have been made to distinguish the voice of the researcher from that of the participants and this is supported, where appropriate, with extracts from field notes and memos.

3.1 Overview of superordinate themes

Five superordinate themes emerged from the data: *A taste of freedom*; *Not having control*; *Getting control back*; *Loneliness*; and *Feeling like a service user*. These are illustrated in figure 12.

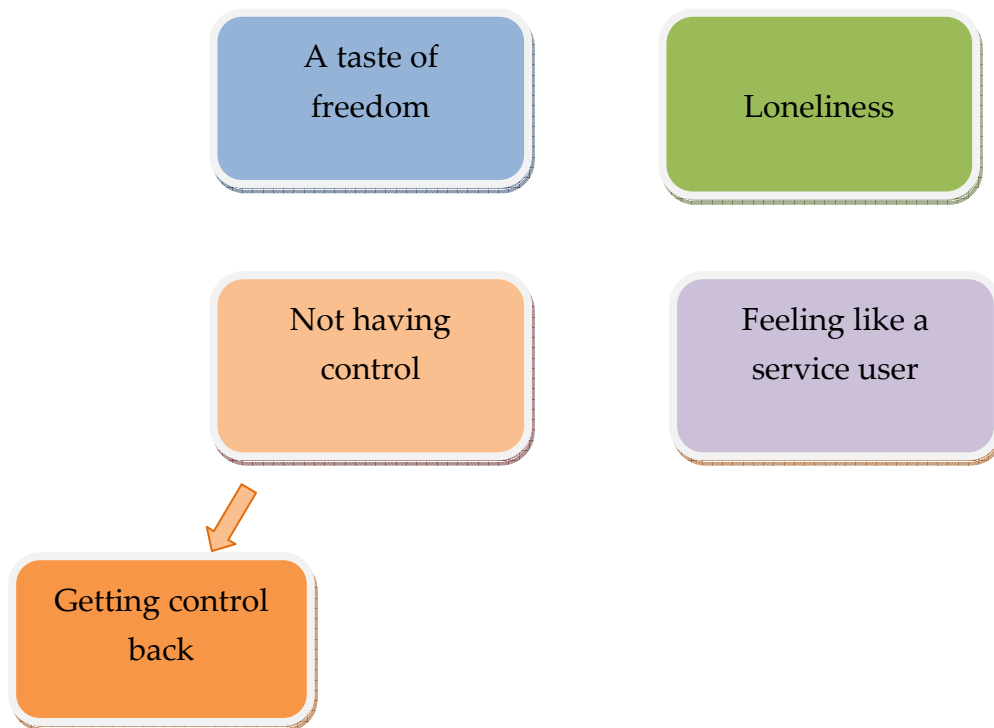


Figure 12 Overview of the superordinate themes

These superordinate themes and their subthemes are fully outlined in the passages below.

3.2 Superordinate theme 1: A taste of freedom

This theme described supported community living as opening up possibilities and increasing the individual's feeling of choice and autonomy. This was often in comparison to other settings in which the participants had lived before, usually hospital. The four subordinate themes contained within this were: *Trying new things*; *Having my own space*; *Doing more myself*; and *Making my own decisions* (see figure 13).

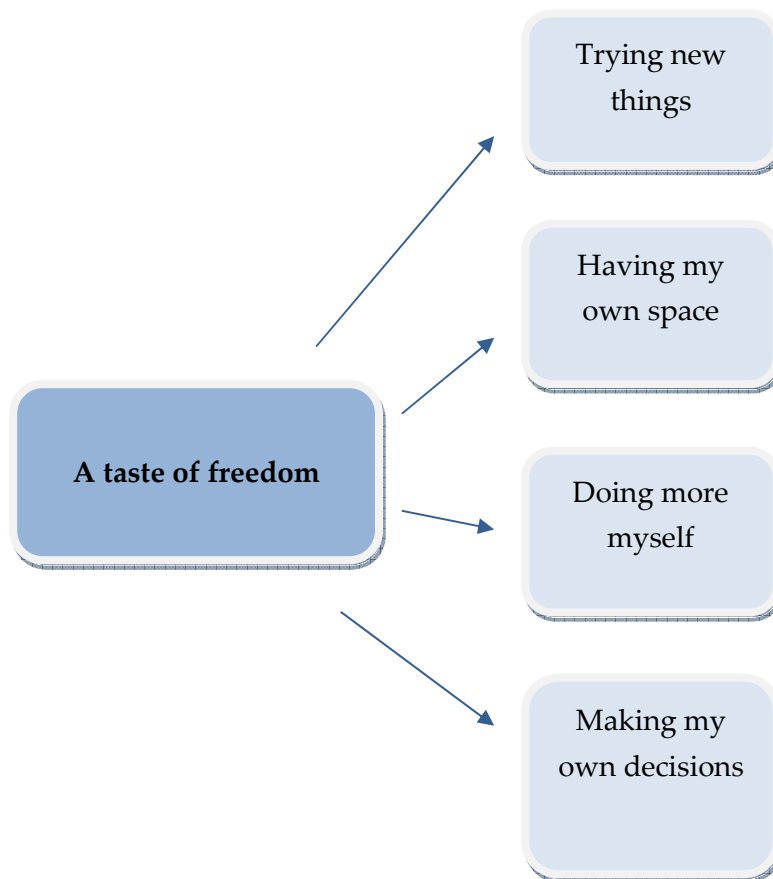


Figure 13 The subordinate themes related to *superordinate theme 1 'A taste of freedom'*

3.2.1 Trying new things

Participants talked about the opportunity to participate in more activities whilst living in the community. This widening of activities seemed to open up a range of possibilities and, particularly for participants who were newer to community living, this was an exciting prospect. There was a sense of wanting to sample as many different hobbies and pastimes as possible⁹.

P: Do, ehm, swimming sometimes.

I: *Mmhmm.*

P: Em...I do, em, [type of]¹⁰ tennis.

I: *Mmhmm...and you've told me you go to the [woodwork centre]*

P: The [woodwork centre], yeah.

I: *And you got to the [placename] garden?*

P: [placename] garden, yeah. (Participant eight: line 852)

This range of activity seemed to increase participants' sense of choice and freedom about how their week was filled and also introduced new activities of daily living which they had not experienced previously, for example planning and cooking meals and shopping for weekly food. This appeared to bring a sense of achievement and normality to their lives, increasing their independence and status as a functional adult.

[...] I like it here because I cook my own meals
(Participant four: line 120)

Well, what I do is, I make, make up my own...my own
shoppin' list and I go and get the...get the, ah, get the
stuff...for, for the next day. (Participant seven: line 19)

⁹ Within quotes 'P' here refers to participant and 'I' to interviewer

¹⁰ In a number of quotes additional details, such as exact activities, dates and so on, which are not directly relevant have been concealed in an effort to retain the anonymity of the participants (as previously discussed within the *Method* section).

The variety of activities available was often in direct comparison to the lack of activities, and resultant roles, available in hospital.

I: Ok. And before...can you tell me a wee bit about what it was like when you lived in hospital?

P: [2 sec pause] Quiet

I: Quiet?

P: Boring, nothing to do. (Part five: line 93)

Participant eight spoke about the opportunity for paid employment.

P: Yeah, I used to go to [Place name] before. Cleaning job.

I: Oh right. Can you tell me about that?

P: Yeah. It was, em, cleaning bathrooms. Bathrooms at [company name]. Toilet and bath and sink.

[...]

I: Right. Did you like having a job?

P: Yeah, I did. Got paid for it. (Participant eight: line 924)

This appeared to have provided a sense of status, especially as he was able to earn money giving value to what he was doing, and perhaps a feeling of self-sufficiency. It may also have enabled him to feel part of the wider world, rather than simply existing within an enclosed community.

Participant four also mentioned being able to go on holiday with staff support. Again this brought a sense of new possibilities in terms of exploring further afield and perhaps doing what 'normal' people do (e.g. Nirje, 1969).

[...] Well, I have staff as, use, help us do things like holidays and that. (Participant four: line 252)

Participant seven also spoke about the experience of discovering new talents, and the sense of achievement and mastery this could bring.

P: Well, it's easier from my, it's easier for me, eh? It just...makes it a lot easier for me as well to, to go out and do things that I've never dreamt of doing.

I: Right. What kinds of stuff can you do now that you couldn't do before?

P: Well, I do a lot of painting, eh? Ar, art stuff. I was never into that before. (Participant seven: line 454)

This appeared to have an impact on this participant's self-identity, as he discovered aspects of himself that he not previously been aware of, perhaps leading to an improved self-evaluation as someone with a range of interests, and even talents.

P: Mhmm, well I wouldae done...since I've been going to the education class, eh? I mean, that's a good bit about it as well.

I: Mnhmm. You being able to go there?

P: Yeah. 'Cause it helps me wi' my, likesa rounding up my CDs to put on the computer and I did. I did that myself. (Participant seven: line 467)

If participants can begin to define themselves in other ways this may open up opportunities, not just for new interests, but for the beginnings of a new self and a new life (e.g. Haaven *et al.*, 1990).

Some of these opportunities were not just about the availability of activities within the community. Both participant seven and participant nine emphasised that these opportunities were only possible via staff support by describing previous experiences in the community when they had been without support.

P: Well, I found it difficult. Not now but I did. Years ago, eh? I found it difficult then. But sometimes it's been, it's been alright living here.

I: Why did you find it difficult before?

P: Because there wer'nae a lot to do, eh? Had nae support, I didn't have anybody to... talk to [...]. (Participant seven: line 293)

I: [...] I remembered you telling me about when you lived in the community before...

P: Yeah

I: And you remember you said you weren't supported?

P: No, no

I: And that that didn't go well?

P: No, no. I was told, 'Get on with it. There's your keys, [own name] – now it's your turn to get on with it'.(Participant nine: line 1438)

There was some reflection and recognition here that support was needed in order to integrate more fully into the community and access all the opportunities which were on offer.

3.2.2 Having my own space

Participants who had previously lived in hospital commented on having more space and privacy as part of the advantage of community living.

You've got your...your own space. (Part five: line 321)

I: [...] in hospital were you living with lots of different people?

P: Yeah

I: So, is it better to be on your own or better to be with people?

P: On my own. Or with people here.

I: With people here?

P: Yeah, neighbours.

I: So, people nearby?

P: Nearby, yeah. (Participant eight: line 814)

Here participant eight seems to be describing a healthy attachment model in that he wants to have people nearby but prefers to have his own separate space as well. There is also an important element of choice to this; he wants the opportunity for interaction, and perhaps support from others, but as and when he chooses.

The idea of privacy is in some ways quite abstract and it seemed to have been difficult for some participants to describe at times. It may also be quite an alien concept – especially for some of this population who have spent a considerable amount of their lives within hospital settings. It is interesting to consider what ‘privacy’ means to this population.

This is illustrated in an extract from the researcher’s field notes:

Team meeting taking place in his house – staff seem to be using it as a core house. People making their own tea, coming in and out. They were offering him tea as well and asking him to go out for a cigarette but even still [...]. What about privacy? Ownership? I wondered if he experiences it like this or if he is glad of the company, or if he just doesn’t know any other way of life?(Researcher’s field notes, 26/11/10)

This observation is from the shadowing session of participant five who felt that he had his ‘own space’. This calls into question whether or not the researcher and participants interpreted the idea of ‘own space’ in the same way. Perhaps the inferred meaning was less about ownership for participant five and more about increased physical space (no longer having to share this space with other patients) and opportunities to be alone at times (even if he was perhaps not able to decide when these times were).

If participants are not able to form a clear concept in their minds of what privacy is, it may mean that it is difficult for them to request it or to know what level to expect.

3.2.3 Doing more for myself

There was a sense of some participants having greater independence while living in the community.

I: ...so when you go to the discos are you with staff?

P: No, no I'll go there myself so I will. (Participant nine: line 363)

Participant nine discusses the independence he has in attending local discos on his own. This seemed to increase his sense of autonomy but also opens up opportunities for independent socialising.

Pilot participant discusses feelings of ownership over his home and his ability to venture into the community without support.

Eh...you'd your own wee hoose, and I got time t, tae go oot to like the shops on my own. Eh...spend a wee bit of time with my maether on my own, eh [...] (Pilot participant: line 496)

This appears to be significant for this participant in terms of a having a presence within the community. It suggests he may have a cursory relationship with neighbours or perhaps shopkeepers at the local store fostering his sense of belonging, one of Ward's primary goods (e.g. Ward, 2002). Pilot participant also talks about spending time with his mother alone, which was likely to be an important aspect of maintaining the intimacy and meaning of this relationship.

It is notable that one participant, however, felt that hospital offered more freedom. There was a sense from this participant that he had to start from the beginning after moving into the community. After having built up various solo activities and becoming 'trusted' within hospital, these freedoms were not transferred on moving out of hospital.

P: Yeah, that's what...that's what it was in hospital time I was there. Soon as I moved from the hospital into here, in...the community, I says hopefully I will get the same thing

I: *Yeah*

P: Hopefully I'll get my freedom – to just to go to the shop myself, or to go down the town myself, but no, eh, eh, it didn't work 'cause staff have...eh, staff have to come with me and make sure they keep me safe from...

I: *Right. And what does that feel like then?*

P: Eh, I felt like...I says to myself, this is rotten – I can't do what I used to do when I was in the [hospital]. (Participant three: line 2077)

As a greater sense of freedom seems to emerge as one of the most positive elements of community-living mentioned by participants, it must be difficult for this participant to view his move to the community as a progression. This is additionally frustrating if he feels he has earned these privileges over a period of time and is now back to square one. This, in turn, may have a negative impact of his feelings of achievement and self-efficacy.

3.2.4 Making my own decisions

Participants talked about having more choice and flexibility in daily activities, which gave them a feeling of ownership of the structure of their week, and a greater sense of control over their life in general.

P: ...my weekly planner day – every Sunday.

I: *Mmhmm.*

P: For the whole week.

I: *And who kinda decides what goes on the planner?*

P: Me

I: *You? So...have you got a free choice about what you put on there?*

P: I...normally take...if I miss...my ironing, know, I put it to the next day. (Participant five: line 44)

I: *I'm just wondering what kinds of things you 'get your own way' with? Is it things you eat? Or what time you go to bed or what, what things do you 'get your own way' with?*

P: Lotta things. I gets'ae eat.

I: *What you eat.*

P: And the time I go to bed at. (Participant four: line 304)

Interestingly participant four spoke about 'getting his own way' in his current placement, as though deciding what he eats and what time he goes to bed at was something he was getting away with, rather than a right that he should expect. Again this seems to indicate the vulnerability of this group having less clear ideas about what they are entitled to, making it difficult for them to know what they should expect from the care system around them.

Participant seven also talked about this freedom as helping him to start thinking for himself, breaking away from the mentality of being in an institution. He speaks as if he had been part of a kind of production line when he was in hospital where there was no need to think for himself as he was just pulled along with the structure that already existed there – meal times, bath times and so on.

P: Or, or the staff will maybe say to, well, not here, eh? But, but in [hospital name] they'd say, 'It's time to get your bath. It's time to get, get ready. It's time to go out. Time to do this.'

I: So everything was quite structured?

P: Yeah.

I: And what does it feel like to be able to choose that for yourself?

P: Well, I choosed it myself because I know I don't have anybody to, to tell me what to do or when to do it or how to do it.

I: Mmhmm.

P: 'Cause I'm actually thinking myself. (Participant seven: line 485)

It feels here that he is almost rediscovering his sense of being an individual, beginning to think about his own preferences and interests. This opening up of possibilities may help participants to see the potential advantages of a pro-social lifestyle (Ward, 2002).

At times, however, participants seemed to describe a sense of finding the ceiling of this freedom, and the realisation that it was not without limits. For some this curtailed the type of activities they could do taking some of the enjoyment out of their experience.

P: Mmm...I'm not allowed to go to zoos, I'm not allowed to go to safari parks.

I: Right.

P: But I love to go to safari parks. Cause I'm really interested in all the animals. (Participant six: line 251)

As well as the realisation that freedom was only partial, these types of restrictions may have also acted as a reminder of the individual's risky past behaviour.

Some participants seemed to accept this ceiling and tried to work within it. Participant seven spoke about exercising choice where he could as he realised there were certain restrictions on him. This seemed an adaptive way of coping with the situation.

P: It just comes and goes, eh? You just...you please yourself when you, likes'ae...likes'ae if I was to, to go out, go do the shopping, I decide when I go out to the shop, eh? Likes of, say, say I wanted to go do the shopping *now*, I would do that.

I: *Mmhmm.*

P: Or, or if I wanted tae, to go for lunch I would go out at lunchtime and just say have a snack eh? And that's it, so...(Participant seven: line 357)

Others seemed to become very frustrated by these limits.

I'm pissed off and scundered – scundered that I...I cannae come...I cannae...hypothetical I cannae come and go as I please to...back in England to see part of my family. I can't go to [...] to see the [family surname]s. (Participant nine: line 1531)

The boundaries themselves seem to be the difficulty for this participant. Rather than actually wanting to visit family, it is the fact that he *can't* which causes the frustration. The feeling expressed is that he is confined, even if he appears not to be at times.

For those who had previously lived in the community, there was a huge sense of loss which came with returning to the world they had once been 'free' in. Pilot participant spoke about what it meant to him to have a job and a partner, as he had in the past.

That means you're bringing a wage onto the hoose. You're, you're getting stuff like furniture for the hoose, tables, chairs, everything like that. You'd be like bringing stuff into the hoose to help her. [...] Used to have a wage in my pocket and anytime I was stuck my mother used to help me [interviewer name] you know? Never short. But noo I feel like when I've got the support workers I've gotta ha' them all the rest of my life. (Pilot participant: line 424)

In this extract the feeling expressed is that the participant has lost, not just freedom, but some of the roles he used to fulfil, being employed; having a wage; and the indirect benefits of these roles in terms of feeling able to take care of a partner and create a home. Perhaps there is some sense here of having lost part of what it is to be a functional adult, or perhaps what it is to be a man. He seems to find it difficult to see how he will ever resume these roles, which in turn, brings a sense of hopelessness.

3.3 Superordinate theme 2: Not having control

The majority of participants described or alluded to a large degree of external control in their lives. This branched into the subordinate categories of: *Not knowing (what the rules are)*; *The system (holding me back)*; *Not having a choice*; *Staff taking too much control*; and *Needing help* (see figure 14).

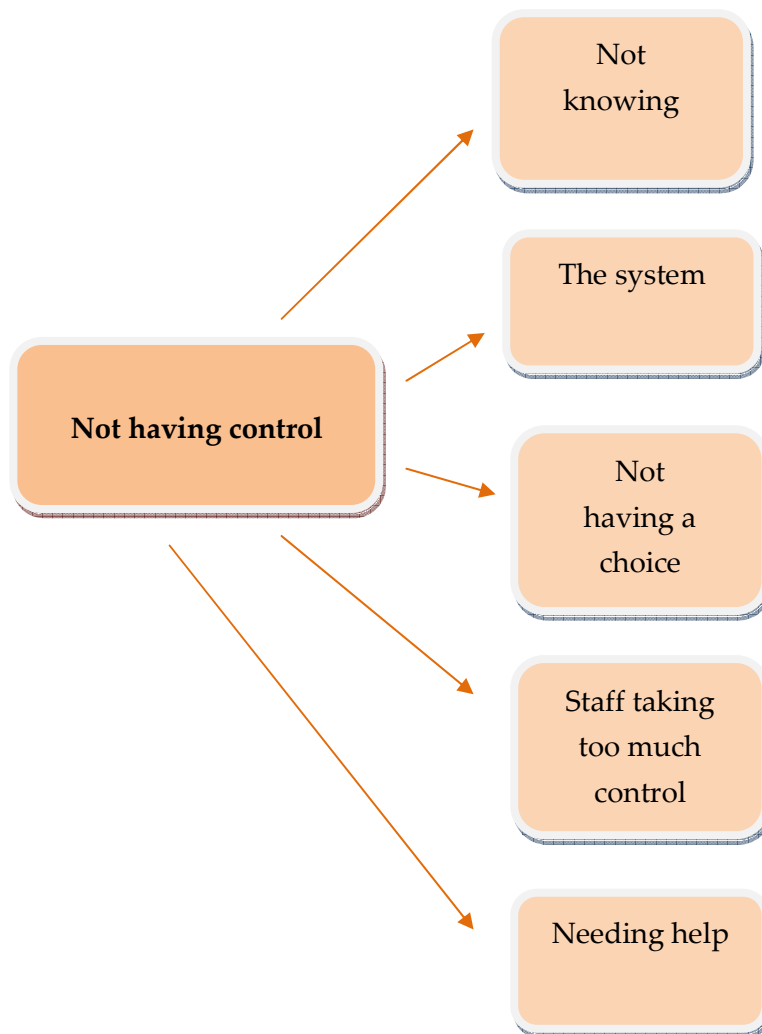


Figure 14 The subordinate themes related to *superordinate theme 2 'Not having control'*

3.3.1 Not knowing (what the rules are)

One of the major issues for participants seemed to be the lack of clarity around a number of different aspects of their care, in particular the exact role of staff and how to move on from support.

Participants expressed uncertainty over why they were subject to staff support.

I: Yeah..so..so you're saying that em...you think it was [social worker; SW], who made...

P: Yes

I: ...the decision...

P: Yes,

I: ...that you need to have staff?

P: That's right

I: And why does she see think you need to have staff?

P: Eh..I've no idea, you'd have to ask [her] that, I've no idea.

(Pilot participant: line 224)

This participant clearly does not see the benefits of support and there is a feeling of being at the whim of professionals. The expressed feeling here is of lack of internal control, in that information is held, and decisions come from, the outside (i.e. professionals, the system).

Similarly, participants did not seem to know why certain restrictions were in place. When asked, they frequently defaulted to the staff member to answer these questions. For example, in the following extract, participant four was asked why the door was alarmed.

P: Not sure because you need to see staff about that because I dunnae ken¹¹ why.

I: That's fine. Yeah. So you're not sure why?

P: No.

I: Ok. What would happen if you went out? Without staff?

P: Because I might disappear or anything like that.

I: You might disappear?

P: Aye.

I: Right. (Participant four: line 348)

The fact that information is held and understood only by others gives a sense of powerlessness to these participants, and exacerbates the pre-existing power imbalance within these client-staff relationships. Without this understanding of why certain restrictions are in place it would also be very difficult for these individuals to question or challenge any of them, which again leaves them in a vulnerable position.

There is a consistent feeling throughout participant responses that they had not ever had the chance to consider and reflect on some aspects of their care.

I: And do you...do you have any free time, or time when you don't have staff at the minute?

P: What do you mean?

I: Do you have any time kind of on your own – when staff aren't here?

P: [4 sec pause] No.

(Participant five: line 232)

Again this emphasised the difficulties with challenging issues that have become so commonplace and accepted that the possibility of life being another way may be difficult for these participants to imagine.

¹¹ “Ken” is a colloquial term meaning ‘know’

I: And do you tell staff you don't like it?

P: No 'cause I hadn't thought about it 'til you asked, ken, I never thought about 'til I said it

(Participant two: line 531)

This lack of reflection by participants raises a concern about the lack of an adequate forum for them to think about and explore these issues. One exception was participant seven who clearly stated the use of an advocacy group as a means of doing this.

There was also uncertainty over the role of the staff team. Most participants identified the main role of staff members as giving support with household tasks.

I: Ok. So why do you think, why do you think staff are there?

P: Just to support me. Help me.

I: Help you?

P: Help me, yeah.

I: Mmhhh. Help you with what kind of stuff?

P: Em, my food. Cooking. (Participant eight: line 1091)

The amount of support that should be offered, however, remained unclear and, for some, this led to resentment as staff members were seen as neglecting their role.

...I used to clean the house on a Sunday and he let me do it all myself. Eh...get the Hoover out on a Sunday, clear my room and that, and he let me do it, all myself you know? I mean I know I'm old enough to do it like, but he wouldn't even brush a...wouldn't even brush the toilet or..he wouldn't do nothing for me, you know? (Pilot participant: line 148)

P: [...] I'm cleaning the house. Why don't they just come in and help? No

I: No?

P: No, no, no, no, they will not come in and help me to clean the house.

I: Right

P: I find that actually wrong actually[...]. (Participant two: line 1491)

This confusion may be expected to emerge as many of the participants seemed to be capable of completing the majority of household tasks independently yet members of staff are with them for a large proportion of the day. Although the staff team may be clearer that their role expands beyond practical help to promoting independent living and risk management, these roles may be less obvious to the individuals themselves. This perception that staff members are sitting back while the participant is putting work in (coupled with the implication in these extracts that the participant felt unable to raise this with the staff themselves) seems to have created frustration. Participants may thus begin to view staff as distant overseers rather than actively involved partners in their rehabilitation.

Interestingly only two participants explicitly referred to part of the staff team's role in rehabilitation. This may have been due to confusion about this aspect but may also have been indicative of a general reluctance to raise the issue of their previous risky behaviour from a social desirability point of view (Langdon *et al.*, 2010). In addition there was some suggestion from participants' accounts that they felt the researcher could help them in some way.

[...] they werene gonna help me or nothing [interviewer name] and I wanna to say this on tape and I want you to take this to [name] as well eh? (Pilot participant: line 50)

They may have felt the need to present themselves as a person worthy of that help by not mentioning anything negative about themselves.

Despite the majority of participants expressing a desire to move towards independent living, there was a feeling of uncertainty for many about how to do this. Within participant accounts of progression there was a distinct feeling of external control as though moving on was something that would happen *to* them rather than a process they were actively involved in.

P: I think it's...I think it's gonna happen I think.

I: *Mmhmm.*

P: I dunnae ken.

I: *Not sure?*

P: Just wait and see. (Part five: line 238)

Well...well, hopefully, if everything goes well, eh, slowly I'll be losing my staff, but I don't know when, eh...'cause it'll be a big...well, it would be a big, eh, meeting, eh...if I was so ...I would be losing my staff altogether and hopefully I'll be starting, eh, going...from here...to my work myself or... (Participant three: line 1656)

The use of language within these accounts, 'wait and see' and 'hope', seemed to indicate participants' feelings of a lack of control over the situation.

Other participants had some idea of how to move forward but this was often vague and seemed to involve simply doing what was advised rather than understanding and integrating this advice.

I: So you'd like to live in [city name] and maybe not have staff in the future?

P: Yeah.

I: And, how could you work towards that? How do you, how would you do that?

P: By listening to what they say. (Participant eight: line 1174)

Due to the lack of clarity around how to move on participants seemed to feel anxious and frustrated about the indeterminate nature of their order, never knowing how or when it was going to end.

*I just worry about – will I ever be free? I'm sure it's it, am I... dunnae get me wrong, I sure this independent living thing's leading me to something. It's got to...it's got to be, you know what I mean? As sure as hell, at the end of the day, they're not doing it for f**k all.(Part nine: line 1528)*

This brought a feeling that they would be subject to compulsory care forever.

[...] why's this gotta be for life you know? We're wanting to try and find out, why's it got to be for life? (Pilot participant: line 320)

Perhaps unsurprisingly there seemed to be a feeling of lack of hope associated with this.

I: And how do you think you would get there, how would you get to that point of having some time on your own?

P: I don't think I'll ever have time on my own. I don't think I'll ever get staying all alone in my house. (Participant six: line 490)

As some participants experienced their community order as a form of being held against their will, rather than a source of rehabilitation, their experience began to feel like that of a prison sentence. It was something they would have to get through rather than something which could help them.

And until...I think...I know [senior staff member] always turned round and said to me I'm not doing a prison sentence or anything like that, and it's not a sentence, but it's...it sounds to me like it's a...it's a prison serv...it's a prison sentence. (Participant nine: line 1471)

Presumably as a result of feeling that this was something they would have to endure, rather than a rehabilitative process, some participants who had been on their orders for a longer period had a strong sense of having 'done my time'.

[...] I just feel, at the end of the day, [interviewer name], that, eh, enough's enough, I've done my time, I've done my sentence – prison sentence or not. I've done my sentence – time to move on now. (Participant nine: 1502)

3.3.2 The system (holding me back)

Participants seemed to feel that the system itself was holding them back at times either in terms of staff acting as gatekeepers; the bureaucracy involved; and the system favouring the needs of staff. There also seemed to be a wider issue of this model of care promoting messages of external control.

Participant two referred to the set-up of the model whereby staff acted as gatekeepers meaning they presented a barrier to contacting people outside the system or raising issues.

But only- see if I had a problem and wanted to see my lawyer? All my staff have... I don't know who to phone, I don't know who to phone, I don't know how to get in touch wi' her. (Participant two: line 1466)

He also spoke about the additional difficulty this caused when raising issues about support itself.

P: But when I go to my lawyer and tell him they come up here and give me a hard-, [care provider manager] come up here and says 'He's only, he's only helping cause he wants money off you'. That's all you get.

I: Right – about the lawyer?

P: I get a hard time every time I go to my lawyer. They dunnae like it, me going there.

I: Right

P: Cause they get the hassle down there.

I: Right so they don't like it when-

P: I ken I'm stuck but I will do it [...]. (Participant two: line 973)

Participant two expresses feeling 'stuck'. The staff team are not addressing his concerns, making him feel forced into taking the complaint through other channels. He seems both reluctant to do this in the first place, and then deterred further by the care provider manager, making it very difficult to see this process through. This seems to make the route for raising complaints extremely difficult for participants adding to this group's vulnerability.

Participant three, however, felt that the senior in his team was not enmeshed in the system in this way and that he put the participant's needs before that of the staff. This seemed to be helpful for this individual participant as it gave him a means of raising issues and complaints in a way that felt safe.

I talk to [senior] about it and...then he's there for...he's there for me, not for...not for staff. (Participant three: line 1579)

Participant nine spoke similarly about a trusted relationship with a senior social care worker who he felt he could talk to and who kept him informed.

...[senior social care worker]'s the only person [...]. He's good at getting up to sit on that side of the settee every week on a Wednesday or Thursday, and asking me what like my week's been and...explains everything to me. (Participant nine: line 889)

For these particular individuals this type of relationship made them feel they had an outlet for raising difficulties as well as a source of clarifying information.

This issue of staff as gatekeepers was also raised when conducting the research itself, reflected in these excerpts from the researcher's field notes and reflective diary.

[...] Difficulties over where the interview was to be conducted – staff flat or the individual's flat. Slightly tense email conversation with the manager about this where she raised risk issues (despite a senior on my last visit not seeing this as a difficulty as there were alarms and the staff flat is right next door to the individual's house) [...] Was forced to conduct the interview in staff flat (as I didn't want to get into an argument with the service manager). Slightly hostile reaction from staff on the day also, noting how it was risky that I didn't have a current disclosure and they were only going on Dr X's word that I was ok, [...]. (Researcher's field notes, 18/10/10)

Difficulties seeping through as the staff realised what the study was about? Protecting the individual as I was not adhering to their policies of current disclosure? Is it their job to be gatekeepers like this, are they permitted to say where I can/cannot interview someone when I have been through a formal ethics procedure and the person has consented? (Researcher's reflective diary, 19/10/10)

These excerpts emphasise that not only is this an issue in terms of participants accessing the outside but also for anyone from the outside being able to access this client group. Again this is a concern in terms of how the views of this vulnerable group are gauged and adequately represented.

Some participants referred to the bureaucracy involved when beginning to engage in a new activity, which caused delays and hold-ups.

I mean, I mean it took them about 6 months to get back to the, 6 months to get back the, ehm, the [Advocacy Service] meeting, eh? [...] Eh, so they're holding me back from things I need to do. (Participant seven: line 184)

Although participant seven was able to understand that risk assessments needed to be completed he felt at times the delays were excessive which meant that he was held back from engaging in community activities.

Participants spoke about feeling that the set-up of the community model seemed to favour staff needs rather than theirs. Participant three explained that, at times, additional members of staff were scheduled to 'shadow' the staff member on shift with him. He explains that this is due to staff members needing to fill their quota of hours rather than providing any benefit to him.

P: 'Cause sometimes I get shadow staff to come with the...with my staff
I: *Mmhmm*
P: Eh...it's just, eh, 'cause they wantin' make up their times, rotas or they're working at the office or some things
I: *Ok. How do you...how do you feel about that? Another staff member coming in just to fill up hours?*
P: Eh...I've felt no uncomfortable two staff, eh, with me [...].
(Participant three: line 1425)

From his description it seems that this participant's preferences have not been taken into account which may convey the message that his needs are, in general,

secondary to the running of the system. Again, this has implications for the participant's feelings of control and the trust he places within the staff and the system.

Participant two describes similar issues regarding the prioritisation of staff needs.

P: [...] [care provider manager] did say something, eh...if I, if I want to go to Edinburgh, if the staff member didn't want to go I did-, I cannae go.

I: If the staff member doesn't want to go?

P: That's exactly what he said to me. He probably say different now, I don't know. Well I've said, 'well I'll just go mysel' then'. And that won't happen 'cause I would just walk out and I'd get into trouble, again. (Participant two: line 957)

Participant two here illustrates the trapped nature of the system both in what he is permitted to do and the way in which he must accept these conditions or he will be penalised. Participant one discusses similar issues.

P: [...] Just [*incomprehensible*] stand at the car park, that's all
I: *So sometimes you just want to go out and stand outside?*
P: Yeah
I: *Why do you want to do that?*
P: To get fresh air
I: *Just to get a bit of – ok...And can you do that sometimes?*
P: No
I: *No*
P: [*firmly*] No
I: *Can you go out the back?*
P: No, that's... that's staff, have a fag, all the time
I: *Right. So...are you not allowed to go there-*
[...]
P: Na
I: *Cause that's where staff smoke?*
P: Yeah. (participant one: line 382)

Participant one here describes his attempts to self-regulate by going outside to try to help manage feelings of anger. This is not possible as the only enclosed outside area he would be permitted to go to alone has become the staff smoking area. This situation seems to give the message that staff members have more ownership over this housing area than he does. Participants may then feel that they have been placed in a staff-dominated complex rather than an individual tenancy over which they have ownership.

Some participants raised the issue of having to pay for staff expenses. Participant two raises this and expressed feelings that this system was unfair or unequal.

P: Yeah, I know. I dunnae like like it eh, I dunnae like it. Cause they're burning the fridge, they're burning the fridge lights and everthin'. They use what I use, it's no' on eh?

I: Yeah

P: I don't mind it but just wish the, the bar, they'd scale it up a little bit and make it... the same [uses hands to illustrate a balance]. (Participant two: line 781)

The system itself also seemed to promote the feeling that participant behaviour needed to be externally controlled. Participant one for example referred to the police being called when he threatened to leave his block of flats.

P: Ehh...[staff member] did phone them [the police].

I: She did phone them -

P: Yeah.

I: - Last night?

P: Yeah.

I: Ok.

P: To say I'm leaving the building.

I: Right. Did you leave ?

P: No.

I: No. She phoned them because she thought you were gonna leave?

P: Yeah. (Participant one: line 258)

This is despite the fact that this participant had never left the building before.

I: Have you ever walked away?

P: No, no yet

(Participant one: line 379)

One participant talked about items being taken as a consequence of displaying undesirable behaviours.

P: Like that's cancelled, and that's cancelled too.

I: *Mmhmm, because you didn't get up?*

P: Yeah.

I: *Right.*

P: Not no getting up, not ...getting angry with staff. (Part one: line 460)

I: *[reading from planner] Getting phone credit?*

P: Yeah that's cancelled

I: *Why is that?*

P: Today, cause, no' working with staff. No, no working with staff. Standing out in corridors. (Participant one: line 163)

For those who mentioned the staff team's role in lowering risk their accounts tended to equate risk-management to staff supervision rather than referring to the development of self-management strategies.

P: They're just ss, eh...supporting me, making sure the public's safe and I am safe – the public's safe and I am safe!

[...]

I: *And how do they do that?*

P: They just keep an eye on what I'm doing. (Participant six: line 447)

This seemed to perpetuate a cycle of promoting external control and failing to promote self-management in this group maintaining their need to be risk managed by others.

Participant eight also mentions the physical restrictions within his home.

I: And, 'cause it's, your kitchen gets locked?
P: It gets locked, yeah.
I: Right, when the staff aren't here?
P: Yeah.
I: And is that, what's that like?
P: Ehm...it's ok.
[...]
I: [...] why is the kitchen locked when staff aren't here?
P: 'Cause I help myself to food. (Participant eight: line 697)

Participant eight described the fact that his kitchen is locked when the staff team were not there which again alludes to the need for physical control and implies an inability to self-manage on the part of the participant.

These messages and strategies did not seem to either model or promote the concepts of internal control for participants. This may explain why themes of external control were often present within their accounts.

P: Eh...living here, I wish I can...go to the shop myself and, eh...take myself but I cannae in case, eh, if anything...if anything crops...if I have a feeling for something...can't do all that, I cannae...
I: Yeah
P: Cannae trust...I cannae...I cannae trust myself
I: You can't trust yourself or staff can't trust you?
P: Eh...staff can't trust me or...or that, so...[...]. (Participant three: line 2020)

Just...keep out of trouble and do em...by mys-...by myself.
Hopefully...well, hopefully myself I...I wouldnae reoffend [...]. (Participant three: line 1907)

Participant one also alluded to external control in requesting medication to manage his behaviour.

And ...eh...whaddy call it, sometimes I like to keep getting a ...tablet, keep me calm and chilled. I no got that yet. I like to get the tablet that keeps me calm. (Participant one: line 272)

Although these strategies may be useful in the short-term, mention of the development of internal coping mechanisms seemed to be largely absent from participant accounts.

For some participants this theme of external control also meant that relationships with staff were reminiscent of a parent-child dyad.

P: [...] I can't remember her name [staff member] but she was a bad influence on me.

I: And what makes you say she was a bad influence?

P: Things I'm not, things that I shouldn't be buying and things that I shouldn't be doing [...] d...adult movies [...]. Dirty movies – all about sex!

I: And why shouldn't you be buying those?

P: Oh I was but it was supposed to be once a month, and like I was buying them every single day when I was out.[...] So that's why she's a bad influence [...]– she was breaking all the rules, so I think she should be sacked! (Participant six: line 548)

In this extract participant six seems to be passing all control to staff and viewing himself as the unruly child who needs to have tight external boundaries placed around him. If participants feel that external agencies provide the boundaries, rather than any internal mechanisms, this may encourage them to take advantage of any opportunities to break the rules.

Participant accounts of how to move on also suggested high levels of external control in that they would either need to completely avoid all risky situations, or achieve complete control over all risky thoughts and feelings.

I'm starting to learn how to get out of that sorta situation, and how to walk away from it, not to get in...not to get involved with it all. (Participant three: line 1330)

[3 sec pause] Have to have stop having sexual attraction towards children [4 sec pause] – that's what I gotta do. Until then I have to have staff. (Participant six: line 496)

There was a sense of hopelessness that seemed to go along with this latter extract, perhaps because the goals seem so unachievable. This also has implications in terms of risk management. If the extinction all risky thoughts and feelings is seen as the goal, then participants may be encouraged to hide these, rather than sharing them with the staff team.

3.3.3 Not having a choice

Although participants seemed to feel they had a choice over everyday activities, wider life choices were less possible. Most participants stated that they would have preferred not to be managed by staff, and were not actively involved in the decision to go on their community order.

[...]they says when I was in [prison] that eh...I wasnae needing support but it was [care provider] manager come to [prison],then [psychiatrist],he, he come to [prison] to say like I'll be supported and I'd be going to [forensic ward], so that was that. (Pilot participant: line 174)

I: Can you tell me about why you think staff are here? Why do you have staff?

P: 'Cause I was told to. I was told to have staff twenty-four hours a day, seven days a week. (Participant six: line 436)

For others the choice was between moving into the community with support or remaining in hospital.

I: And do you need them?

P: Ah, I say "No" but I'd nae choice.

I: Right

P: [...] I took, I took about a couple of weeks to think about it, eh? [...] So basically, em, I was saying, I was saying to [.psychiatrist] that I didn't need staff and he sorta said, "Well, if you dunnae keep staff you'll no' be, you'll no' be getting out so-

I: Mnhmm

P: - I had a choice to make, eh? (Participant seven: line 345)

It is interesting to note the interaction between participant seven and the psychiatrist, and the way in which this participant thinks about his situation, as it allows him to reframe this decision as his own choice. This has very positive implications in terms of his feeling of internal control and his view of himself as actively involved in his care and treatment.

Participants also expressed discomfort in the fact that they had no choice in who they were supported by.

Well, I don't know how I'd stand with that but the point is, em, they're trying to see if I can get money from the government in Scotland to go into my bank account, to pay who I want to employ as my staff. (Participant nine: line 1176)

The issue was not just about choice in itself but also related to an obligation to work with staff members whose views or personal style clashed with that of the participant.

P: [...] He's just one of they persons, he just jokes about them but I dunnae like that.

I: Ok so it makes you feel uncomfortable.

P: Aye. Just like [ethnic group] and he hates them and all the rest o' it. But I wish he'd keep that sorta thing to hisself. (p2: 258)

Some participants did mention some involvement in choosing members of staff, although not necessarily those who would be on their core team.

P: I'd pick the new staff, I would prefer to have [lists 4 female staff members]. But – I'm no' allowed to choose staff

I: You're now allowed?

P: No [...] The only thing I'm involved with is actually interviewing staff, interviewing people who want to work in the service [...]

I: And is that good

P: Yeah I enjoy doing it aye [...]. (Participant six: line 82)

The impression from participant six is that this is something that he objectively enjoys this rather than a process which makes him feel his opinions are directly impacting on the service or his care.

3.3.4 Staff taking too much control

There was a sense from participants that some staff members seemed to cross boundaries at times. This seemed to happen either advertently or inadvertently via the staff member failing to adequately take account of the power differential.

Participant two, for example, describes an incident with the care provider manager which left him feeling intimidated.

P: I cannae remember. I can't exactly remember 'til I do it again. But I'm scared to do it -, I am actually scared to say it again.

I: *Mmmmm.*

P: Cause he would just come up here and go, like, he had like an attitude towards me. Cause he just says 'you're getting £5 that's enough' but a bit o' kinda like an attitude, I mind that. (Participant two: line 746)

From this example it may be important for staff members to maintain an awareness of how clients may perceive their tone and body language, given the power differential implicit in these relationships. This is important both in terms of pro-social modelling and building a trusting relationship in which rehabilitation can be effective.

Participant nine also discusses staff overruling his requests.

P: Because he...he had went and got his papers and his own cigarettes if he needed them, and he says "Come out now". I said to him, "I want to have a fag myself" and he says, "No, I'll have a fag with you". (Participant nine: line 1049)

Again it seems that an awareness of the delicate power balance is important. It appears difficult for these participants to see themselves as functional, autonomous adults when their needs can be refused. This, again, emphasises the need for staff members to remain aware of the delicate power balance in these relationships.

Similarly, some participants also referred to staff trying to exert control over non-risk related issues. Participant nine recounts an incident where a staff member attempted to deter him from buying an item of clothing similar to one he already owned.

P: [...]He...because of the, what d'ye call it now, the blue coat, em...he took me outside the shop and said, like, "What time is it? We're going home". That's...I told him straight, [...] Because I wanted the blue coat instead of the black coat.

I: Right.

P: Because the, the blue coat ... was something similar to a rain jacket I had before now. I think he was just a big bairn and needed to grow up.

[...]

I: So just let me make sure I'm getting you right. So you're saying you ended up buying the black one?

P: Instead of the blue one.

I: Because [staff member] had wanted you to get the black one?

P: Yeah, yeah. (Participant nine: line 948)

This extract seems to be about a battle for control of the situation, which appears to be unrelated to risk. This may be a consequence of a lack of clarity about the boundaries of what kind of behaviour the staff team should and should not be managing.

Some participants felt that they were treated disrespectfully by the staff at times.

I: Do you, what do you think about having staff?

[3 sec pause]

P: Not that good

I: Not that good, ok

P: Cause...I no like when folk isn't speaking... nicely ... [trails off]

I: You don't -

P: - nicer

I: - you don't like that?

P: Na

I: You think they sometimes don't speak -

P: Yeah

I: - nicely? Ok

P: Yup

I: What do you mean, what do they say?

P: Shoutin'. (Participant one: line 211)

The way they act, their attitudes and some of the things, like [staff member]'s got an attitude sometimes he comes in, he's got a moody attitude and a wee bit later he's all happy and a wee bit later it's- he can be moody, I can tell [...] I feel like saying 'if you're gonna be like that, just go back home, just go out the door and dunnae come in'. (Participant two: line 1771)

The system is run by a human resource and personal issues or conflict are therefore unavoidable at times; what may be more pertinent is how these interactions are dealt with. It seems from participant accounts, if unresolved, these negative interactions can result in resentment and a loss of trust, which has implications for the rehabilitative value of this model.

Difficulties with maintaining boundaries appears to be exacerbated even further by the fact that participants' homes effectively doubled as a staff workplace.

P: She doesn't do her dishes some mornings and she doesn't do dishes. She gets her tea at night, she doesn't do her dishes. She does them in the morning. I have to live with that all night.

I: Right

P: And if she treats it like that, I wouldnae be cleaning. I would just leave mine too eh.

I: And are you able to say to her that you don't like-

P: Na, cause I like the person

I: Yeah

P: And that's the hard – cannae get round that one.
(Participant two: line 1564)

Participant two here expresses having pride in his home but that this is difficult to maintain due to sharing his home with staff members, whose preferences may differ. The opposite also seemed to be the case within other participants accounts in that many were cleaning parts of their house daily.

I do housework, laundry, and ironing on the Monday [...]. Tuesday, [...]. Change bed, wash bedding. And, em, shopping on a Wednesday [...] Housework. Relax at flat. Thursday, [...], cleaning kitchen and bathroom. (Participant eight: line 186)

It is unclear whether it is the participant's choice to divide domestic tasks in this way or whether this is related to a general approach to all supported clients. This is a difficulty in that these participants' homes do serve as work places and may therefore need to be kept to a certain standard of cleanliness. This, however, may impact on participants' identities or sense of choice. This is a complex issue and was considered in the researcher's reflective notes.

I was previously thinking 'is it right to have client's clean parts of their house everyday – is that their choice or not? You should surely be allowed to clean as much/little as you like.' Whilst shadowing, however, I had to use participants' bathroom and at one point made some tea and realised that I wouldn't be happy to work anywhere/eat anywhere that was really unclean. Difficulties with the home also being a work environment for staff. Difficulties also with putting yourself in the shoes of staff until you are in that situation yourself. (Researcher's reflective diary, 13/12/10)

Participant two makes another important point. He feels unable to raise his grievances, at least in part, because he has formed a relationship with this staff member. Although these relationships may be generally positive they also create yet another perceived barrier to raising issues. Other participants talked about this as well.

I: Mmhhh. And what makes it hard to say that to staff?

P: Eh...very difficult! Very hard for...well, I don't want to be...nasty to them. (Participant three: line 1802)

As well as being concerned with the power imbalance, this section clearly demonstrates the complexity of staff-client relationships which are difficult to manage for both parties.

3.3.5 Needing support

Another factor feeding into the lack of control was participants' ongoing need for support. This support was with practical tasks, but also on a more complex emotional level.

They have to pay my bills, sort my direct debits and everythin' oot.

(Part five: line 156)

I: What do you like about him?

P: Speak to him, speak to [staff member] if there's... problems.

I: Ok. You feel like you'd be able to speak to him?

P: Yeah. (Part one: line 694)

'Cause it...'cause I can tell them how I'm feeling...(Part five: line)

Staff also fulfilled a protective function due to participants' potential vulnerability within the community.

So make sure everything's alright, and make sure everything's fine, make sure I'm safe and everything like that you know?

(Pilot participant: line114)

This protection was important not only in a general sense of the vulnerability of people with LD to crime and exploitation but also in relation to community hostility due to their past offending.

P: Because there's a lot of bad memories in [town name], eh?

There's...

I: Right

P: There's folk want to hammer you or kick you or something. (Participant seven: line 308)

In case anything happens to me or if eh, anybody comes up and says like, ...start... beats me or give me trouble or say something[...] It's...it's something like that but if somebody I, somebody recognizes me and goes 'there's that... mm...eh, paedophile' or something like that, it's...

(Participant three: line 910)

Although these aspects of support are positive, they also seemed to create a dependency on staff support. The double-edged nature of staff support as both protective and restrictive is illustrated by an extract from participant seven. He begins talking about stigma as a downside to having staff support but, as he goes on, his account begins making reference to the protective function of staff.

I: So is that a good thing or a bad thing that people don't come and talk to you?

P: That is a good thing.

I: It's a good thing.

P: But it's not a bad thing either. For sometimes if I ken somebody they'll come and talk to me.

I: Mnhmm.

P: But I just know that doesn't happen very often.

I: So is it good and bad then? 'Cause it protects you but it also makes it harder for people to talk to you?

P: Yeah. (Participant seven: line 407)

Within this extract participant seven seems to struggle to make his point. Initially he seems to be saying that having staff support prevents day-to-day community interactions but goes on to describe how community interactions have been a negative experience in the past and staff presence is therefore preventative. This reinforces the idea of staff as both a protecting and a restricting element of the lives of these men. Though necessary in many ways the structure of support creates a number of self-perpetuating difficulties

making it hard for participants to lead normal lives and progress towards independence.

Understandably, there may be some ambivalence from participants about moving on, especially if they have been on their order for a long time and are used to receiving this support. For example despite being on his order for a significant period and expressing a desire to reduce staff support participant three still seems reluctant to raise this through formal channels.

I: Right. OK. So you're hoping, then, that over time you'll have less and less staff?

P: Mmm.

I: And then...until there's no staff or staff sometimes or...?

P: [...] So hopefully it'll gradually... well, it'll build up.

I: Mmhmm.

P: Eh...wi' myself...if they're gonna trust me, yes, I'll go.

I: Mmhmm.

[...]

P: I havenae, I havenae, eh...put that question, eh, forward to the-, with...to, eh, [care provider manager] or [senior support worker] or...what's gonna happen. (Participant three: line 1860)

There is strong sense of external control, again, in this account but there also seems to be some ambivalence around the issue. It may be that, if not actively encouraged, participants feel safer to leave things as they are. Without being driven forward in some way participants could stagnate within this set-up as evidenced by the 'wait and see' nature of their accounts.

3.4 Superordinate theme 3: Getting control back

Participants seemed to have different reactions to the lack of control as outlined in Theme 2. For some it was about finding a means by which they could regain control, either actively (*Taking control*) or passively (*Holding back*). Where participants did not attempt to regain control, another potential strategy emerged (*Giving up*). Some participants seemed to feel they were fighting a losing battle and had instead become resigned to their current situation (see figure 15).

Participants did not necessarily fall exclusively into one of these categories, some described using different strategies at different times, but often they were predominantly adopting one or another.

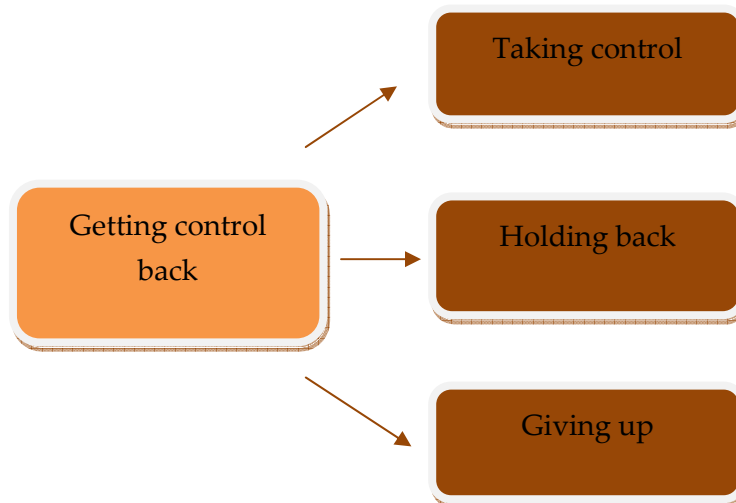


Figure 15 The subordinate themes related to superordinate theme 3 'Getting control back'

3.4.1 Taking control

Active means of taking control discussed in participant accounts included using formal channels to voice any issues, for example speaking to senior staff members/managers.

[...] I spoke to [senior support worker] and I says 'look something clicked in my mind and I cannae discuss it with staff, can I come to the office, and help you, talk to you about it?'. He went, 'Aye, no problem, [...]'. (Participant three: line 1569)

Some participants also talked about the use of Care Programme Approach (CPA) meetings as a chance to formally seek further independence.

I: [...] So, em, you mentioned your CPAs?

P: Yeah.

I: Could you tell me about those?

P: Yes, I ha...I'm a...I'm a...I'm a special guy. I get my CPA meetings once every three months-

I: Mmhmm.

P: - for my independent living. I do...I do all three requests myself [...]. (Participant nine: line 192)

This seemed to instil a sense of self-efficacy and pride within this participant as it was something he prepared and presented himself in order to progress.

Participant seven also expressed similar self-efficacy with a desire to become more actively involved in his own care.

Well, whoever it was, I was goin', because it's, because it's involving me, em...I don't see why...I don't, I don't seem to see why they ask you to go wi' a member of staff to do a risk assessment on myself 'cause I think it's important that people, like myself, do a risk assessment with staff so, so that they could pick up, maybe, maybe they'll, maybe I'll pick up somethin' that they didn't. (Participant seven: line 204)

Becoming part of the risk assessment process seemed to be a way in which this participant could gain knowledge and understanding of the system he was in. This knowledge may then help him to negotiate his way around, and eventually out, of it.

For some, advocacy groups, as independent organisations, were used as a means of expressing views and trying to elicit changes in the system from the outside.

Ah, it's basically...helps, helps some of the members tae, to look at different points of how...how their feeling, how things are, eh? And just basically, em, just talk about things that are important to them and how they, how they feel and stuff. So, that's basically what [advocacy group] is all about. (Participant seven: line 248)

Alternatively some participants used a lawyer as another outside means by which to address difficulties within the service.

[...] It's going to my lawyer, if I can get someone to put it in writing. Cause it's no, that's no right, that's no, they cannae do that, they're here to support me and..that's, that's wrong. (Participant two: line 967)

Participant two described this as though it was an extreme measure, a last resort, emphasising his feelings of being unable to affect the system from the inside. This, again, has echoes of external control.

Whether or not this strategy of actively seeking control was adopted appeared to be influenced by how able the participant was, both to understand the system and to clearly express their own views. Participant two, participant seven & participant nine who brought up the use of active control demonstrated both knowledge of the system and ability to clearly communicate their needs. For example participant seven was able to accurately describe the purpose of carrying out multi-disciplinary risk assessments.

Ehh...well, it's basically just, eh, folk decide for, for people like myself, eh, go to...if I was going anywhere you would get risk assessed, make sure that we're safe, for myself and the public. (Participant seven: line 129)

A key aspect was that these participants were able to understand the system enough to question aspects of it.

[...] why...why should I do, do anything for to get risk assessed when ma staff, eh,...'cause it's no like [distant place name]or anything silly. (Participant seven: line 213)

P: And they got a hard neck to gi' me a £5 note towards the fuel bills, cause I'm too, I'm too soft wi' it. [...]. They've got a TV in the staff room

I: *Mmhmm*

P: I dunnae mind that

I: *Mmhmm*

P: I do get £5.... they think it's so good cause they gave me £5, but I fought, I fought for that. Ken? I went through lawyers to get that. (Participant two: line 705)

Participant nine was also able to question the order he is subject to.

I'm not a murderer, I'm not a paedophile, I'm not a drug dealer, I'm not a...child killer, I'm not a terrorist and sure as hell I'm not a bank robber. But I'm still getting detained because of my schizophrenia. That's really an infringement of my human rights.(Participant nine: line 1506)

Participant seven also seemed to have the ability use staff as a form of empowerment rather than restriction and was clear that they only provided support when necessary.

[...] I've got my shopping list. I just do the shopping...on my own, basically. They are there if I need them, if I'm stuck or anything. (Participant seven: line 99)

This is an important issue. Although positive in these particular cases, it also raises a counter-issue of what happens to those who are less able to express their views either due to a more significant intellectual impairment or simply a lack of assertiveness.

3.4.2 Holding back

The subtheme of holding back referred to passive means of control which included choosing whether or not to engage with staff members, refusing to do things, or being surreptitious.

[...] I went 'no', I'm gonna loss it all, I'm just going to have to be down in the dumps and, eh, not to speak to staff or whatever...(Participant three: line 2180)

P: So that's why I want to, eh...eh...to get, get back to [senior staff member] and say 'Look, can you ask your staff to either sit across from me or sit behind me?' If they don't do that I'm no' [...] I'm not gonna go. (Participant three: line 1795)

Participant three explains that he will attempt to negotiate with staff but if this fails then he will resort to what seems to be a form of passive control, in his

refusal to go. Participant three describes an aggressive ultimatum style approach which is likely to be received negatively by the staff team. This raises issues of, not only participants' understanding, but their ability to make requests in a way that is appropriately assertive, and therefore will be effective. Participant three discusses this difficulty himself in another extract.

P: I cannae say that to them, eh, because...I'm, eh...I would probably say I'm feared of them, or... I'm scared, eh, to say to them...

I: *You're scared to say?*

P: Say, yeah

I: *What do you think would happen if you said it?*

P: Eh, if I say that to them they'll probably phone [senior] and say, eh...that's [participant name] [2 sec pause] losing his temper with staff.

I: Right. So they'd see it like you getting angry?

P: Angry, aye, or losing my temper or...or...well I'll probably not ...but I'll just probably kick up a row or...(Participant three: line 1809)

Participant two talks about sneaking in extra alcohol. He gives the impression that he will be denied this additional supply if he asks upfront, so he finds alternate means of meeting his needs.

Well they said I can only have two. Two a week and eight... No sorry, two a day and eight a week. But *they* dunnae realise I'm getting the big bottles, two big bottles [laughs]. I got away with that forever. (Participant two: line 1073)

Again there is an implication here that participant two would be unable to self-manage his alcohol intake. This may be an historical fact, however the strategy employed seems to exclusively use external limits rather than helping this participant to develop skills in order to self-limit.

For others a 'keep your head down' type approach was employed, hoping that if they caused minimal fuss things would continue to move in the right direction. Participants in this group seemed to be one of two kinds. The first were those who had not been on their order for long, and perhaps therefore remained hopeful that they could move on quickly.

Working with the staff, take one day at a time. (Participant five: line 295)

Participant eight seems prepared to wait for his time to come and still places trust within the staff and the system.

Participant nine on the other hand has been in the system for much longer and seems to have learnt that this is what you *need* to do in order to move on.

P: [3 sec pause] By...being a good little boy and doing everything that's asked of you, and treat everybody else the way you like treated yourself, and moving on from there, with your independent living to get your...goals of...this year or whenever.(Participant nine: line 1599)

[...] I'm keep on nowadays progressing with my independent living. I'm not giving any of these professional people any excuses or any cases to argue. (Participant nine: line 871)

These two types of participants seem to demonstrate something about the system; it seems to deter use of internal control both implicitly (by not promoting self-management from the beginning) but also explicitly (by deterring it's use). As previous, this approach also has implications for participants not being upfront about risky thoughts and feelings as their attempts become more directed at getting out, rather than getting help.

3.4.3 Giving up

Not all participants tried to regain control, some instead seemed to feel a sense of resignation about the way things were and felt it was not worth trying to change anything.

I just don't wannae go to eh...meetings and, nothing gets done like. Go to a meeting and ho- I be building my hopes up, right? I'm gonna get this, I'm gonna get this. It doesnae happen, you get telt to go away and come back in about a month's time. Go away, come back with another staff- I dunnae want to build my hopes up like that. (Participant two: line 1802)

I: And is there...is there somebody you could talk to if there were staff you didn't get on with?

P: [care provider manager]. [care provider manager] says he knows what staff's best for me, not-...so, what's the use?

I: So you feel like there's no point in talking to them about it?

P: No, it's like talking to a blinking brick wall. (Participant six: line 371)

Both these participants feel unable to affect change within the system and have therefore resigned themselves to staying as they are. From participant accounts this seemed to have a general effect on feelings of self-efficacy and on hope of having a different life.

It is worth noting that one participant (participant four) was happy with his current circumstances and did not employ any of these strategies to try to regain control for this reason.

I: Right. What do you, what do you kind of hope, when you think about how things will be in a year or in two years, would you want things to be different than they are now?

P: No.

I: No. You're happy with the way things are?

P: I'm quite happy with the way things are. (Participant four: line 387)

Issues of control and feeling trapped were not therefore the same for all participants but did apply to the majority.

3.5 Superordinate theme 4: Loneliness

More than half the participants discussed feelings of loneliness related to the presence of a limited social network to begin with, and further difficulties in forming and maintaining relationships while being supported. As a result staff members appeared to become a source of companionship. The subordinate themes contained within this superordinate category were *'Not having anyone'*, *'Support making it hard to see people'* and *'Staff as company'* (see figure 16).

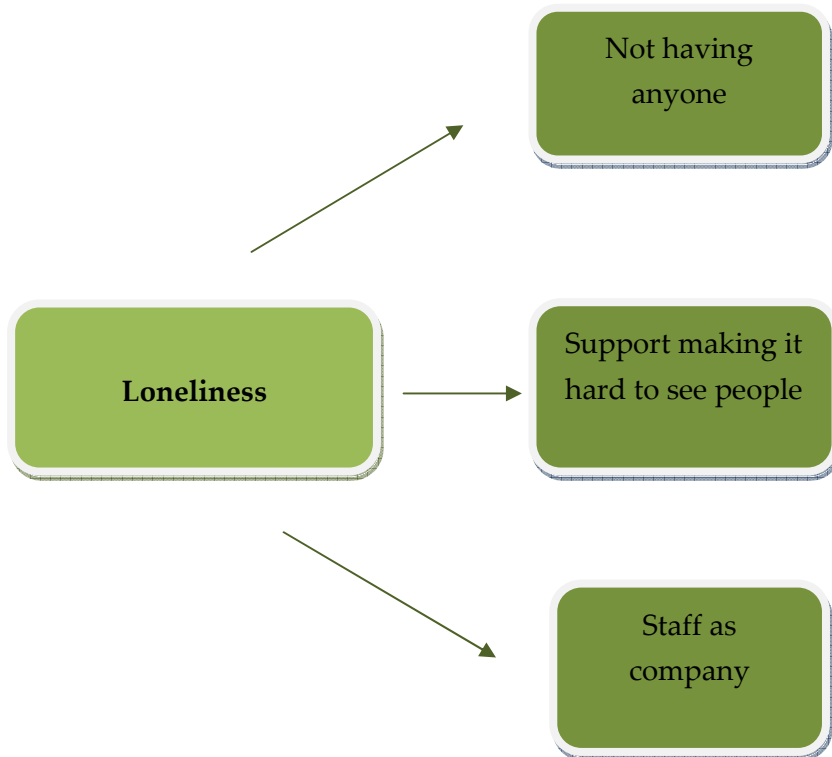


Figure 16 The subordinate themes related to superordinate theme 4 *'Loneliness'*

3.5.1 Not having anyone

Many participants described a sense of loneliness or isolation and a desire for more of a social network.

*I: That's right, 'cause you play the lottery, don't you? [laughs].
And what else would be different? So you'd have lots of money...*
P: Lots of money, friends would come out of the woodwork.
(Participant five: line 300)

[...] I'm on websites like facebook, I'm trying to find pals cause I no get very many, I just..I lied, I did say earlier that I didnae want pals, but I'm trying to find friends. (Participant two: line 1588)

As well as having few friends, unstable family relationships were also a common theme within the interviews.

[...] my brother's always sadly let me down when every time he's been at a CPA meeting – eh, he's always had some sort of, this and the next thing, of problems he cannae make [...] I think I packed in the swimming at the [place name] 'cause I...my original plan was to go and see my mum after that, but that all fell through – she had her own problems, she couldnae see me. (Participant nine: line 811)

P: [...] I go on and I smell alcohol, I'm out the door again, I cannae be bothered with it,
I: Mmm, steer clear?
P: I do, I cannot be bothered with it. My mum's like that. [...] She starts...she doesn't even ken what she's doing.
(Participant two: line 1249)

Of course as well as leaving participants in an isolated position these family dynamics have significant impact in terms of the individual's ability to form relationships with others (Bowlby, 1988).

This loneliness was reflected in the fact that several participants did not seem to want the researcher to leave following shadowing sessions.

Felt bad when I left, felt he didn't want me to leave. It was lunch time and he said 'I don't have lunch some days anyway' [...] I had stayed for the half-day though and we were just going to be sitting in the house so it felt a bit intrusive. Plus I hadn't had lunch! Loneliness? (Researcher's field notes, 26/11/10)

3.5.2 Support making it hard to see people

Participants' loneliness was exacerbated by the fact that support made it difficult to form and maintain relationships due to the being consistently supervised.

Eh...because I've got staff 24/7 and I cannae get a girlfriend. I cannae get nob'dy, I cannae go to the dancing, I cannae go tae the [...]...the discos. And I just cannae pick up anybody I wan', I've got to start wi' talking to somed'y about this. (Pilot participant: line 274)

We were in...we were at the [restaurant] about a fortnight ago, eh...she sits on her own again, she asked the staff to move on because she's trying to talk to me privately, about the family and everything, and it's really ridiculous, I cannae get time to speak to her. It's really scandalous like, we cannae get time to speak. (Pilot participant: line 296)

Some participants spoke about the possibility of financial exploitation by family members meaning the staff team had a duty to supervise these interactions, potentially disrupting the intimacy of family relationships.

P: [...] if I dunnae give my mum money, my mum's no' gonna to be happy. (Part five: line 263)

I: Right... Ok. So how come you, staff are there when you see your mum?

P: Because she... I'm no allowed to give stuff to her.

I: You're not allowed to give stuff to her?

P: No.

I: Right. What kind of stuff?

P: DVDs and CDs

I: Right...Why's that?

P: Because it's, she'll ask. (Part one: line 563)

In the following extract participant five discusses his mother's visits and her tendency to converse with staff members during these visits.

P: Sometimes I feel as if my mum's coming to visit me, no' the staff.

I: Mmhmm. Can you tell me a wee bit more about that?

P: Staff should go on and do their own thing. (Part five: line 251)

This may be indicative of staff becoming overly involved in these interactions but the resentment expressed by participant five may also indicate a lack of intimacy in the relationship with his mother which is highlighted by a third party being present.

Other participants commented on the stigma of staff support being a barrier to forming new relationships.

P: Aye – ha'ing staff. I got to lie. But the second time you go and meet them with someb'dy else, 'who's that?'. 'Oh aye, that's my brother'. You cannae, you cannae win that way eh?

I: Yeah.

P: I think about it, I think it's just better to just keep myself to myself. (Participant two: line 1614)

3.5.3 Staff as company

Most participants were isolated already because of their housing situation and unstable family relationships, no doubt exacerbated by having a pre-existing LD which is likely to have caused social difficulties in any case. In addition staff

seemed to create a barrier to forming relationships meaning that the main relationships for these men were with staff members.

It is not surprising then that participants described carrying out activities with staff, eating meals with them, holidaying together, thus providing not only support but what sounded like a sense of companionship.

... have a joke with them, tell them to 'p off'. (line 214)

P: They planted, they planted the heathers in the grass.

I: *Oh it's the heathers isn't it. Mmhmm. So who did that?*

P: Me and [senior staff member].

I: *You and [senior staff member]. Oh ok. Good.*

P: Huh, no it's no us, not me and [senior staff member] that done that, that side. [staff member] done that side.

I: *Right so it's the other side you did?*

P: Yeah, the other side. (Part one: line 840)

...We usually go for a meal on a Saturday night. (Participant nine: line 1299)

The isolation and loneliness expressed by participants and the companionship they found with staff therefore had a danger of becoming self-perpetuating.

[...] if you are going out for lunch you don't want to eat alone. BUT would it encourage more socialising if staff weren't eating with them? Encourage them to ask someone to lunch if they wanted to go out. This applies to other activities as well e.g. cinema. Staff becoming befrienders rather than support? Creating an interdependence rather than facilitating independence? (Researcher's reflective diary, 13/12/10)

Participant two seems to be describing this when he explains that, although staff do not help him with many practical aspects of his life, he would feel 'lost' if they weren't there.

P: I don't know if it'd be..., I'll be really honest, I think I'd be lost

I: You think you'd be lost? Right

P: If it was during the day anyway I'd probably just, I'd be lost, honest I would

I: Tell me a bit-

P: Til you get used to it, til I get used to being alone again eh? (Participant two: line 557)

The more participants rely on staff as companions, however, the more it seemed to isolate them further within the community, reducing their chances of gaining an independent social network.

Although there was a general theme of isolation throughout participant accounts, even via an omission of reference to social activities, it is still important to note that some participants did report some ability to form and maintain social relationships.

P: At night, visiting people.

I: Visiting people?

P: [staff member]-

I: Like [staff member] was talking about, visiting [name]

P: Yeah.

I: That sort of thing?

P: Yeah.

I: Sometimes that's good?

P: Yeah.

I: And [staff member] sort of mentioned em, parties as well that you have

P: Yeah.

I: What's that like?

P: Good. (Participant one: line 436)

Similarly, not everyone saw staff support as a barrier to family relationships.

P: Ah, that's no problem, just that they...certainly if they need to, sometimes they do stand there but...and have a wee

chat with them all, they go to the room, the staff room and do a bit of paperwork

I: So they sometimes give you a bit of space with your parents?

P: Mmhmm. (Participant six: line 304)

I: And what's that like – being with your mum, with the staff there?

P: The staff talk to my mum and I talk to my mum [...] sometimes mum talks to me, and I talk to mum and staff talk to mum and...

I: So it feels OK?

P: Yes, it feels all fine and things like that so...(Participant three: line 1140)

This gives some sense of hope that the system could potentially support the building of a social network. It may be useful to consider what types of participants this worked for and why.

3.6 Superordinate theme 5: *Feeling like a service user*

Another distinct theme described by participants was related to the stigma they felt within society and their reactions to this. The subordinate themes contained within this superordinate category were, *'Feeling different'* and *'Trying to be normal'* (see figure 17).

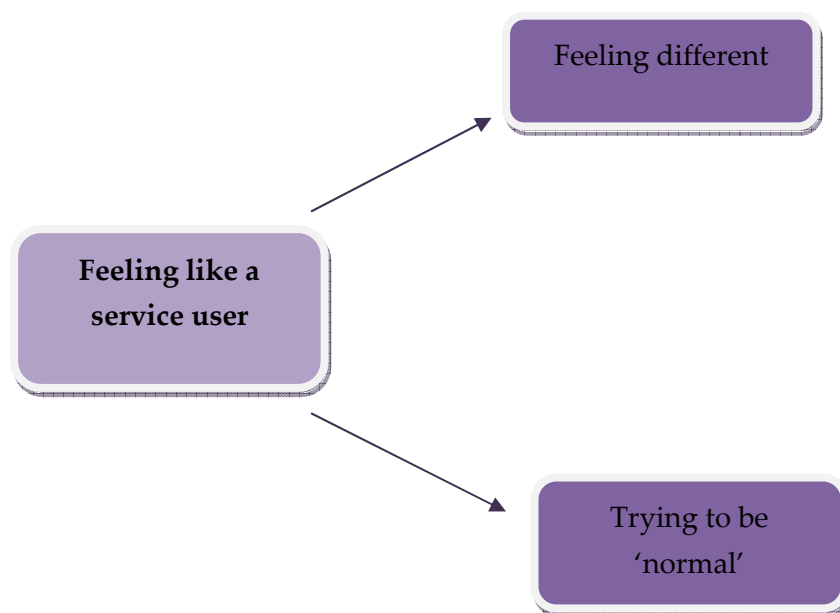


Figure 17 The subordinate themes related to superordinate theme 5 *'Feeling like a service user'*

3.6.1 Feeling different

Around half of the participants spoke about some form of stigma being attached to receiving support. Many referred to support as a symbol that they were unable to look after themselves.

I mean my dad says 'why you still got support at this time?'. I mean, every time he wants to ken about this when he's no interested about [care provider]. 'That support workers, h...why you still got them at this...your age?' (Pilot participant: line 501)

Interestingly there seemed to be more shame associated with needing help taking care of oneself than being seen as a risk to the public.

P: [...] 'cause people...the people will see, they'll see me as...they'll maybe, people see me as...that I can't look after myself [..] They'll say, "Oh, look at him, a'him or her or him", eh? I dunnae get any reaction it's just that sometimes people see maybe... staff, eh? But they dunnae ken...they dunnae ken why I need the staff, eh? So...(Participant seven: line 371)

Participant seven here also brings up the fact that people are not necessarily looking at him but that these are his anxieties about what others *might* be thinking. The stigma of having a LD for this man seems so great that he implies he would rather people knew he was an offending risk than think he could not take care of himself.

Participant two spoke about trying to disguise the fact he was being supported by pretending that staff were relatives or friends.

P: ...Em, I'd rather go out and kid on they [staff member]'re my mum or my sister or something, or an auntie. Better that way, it sounds better, feels better

I: Yeah, I understand-

P: There's nothing worse than going down the street 'Oh I'm supporting [own name] the day, this is [own name], I'm supporting him'. I wouldn't like that, but that's embarrassing.(Participant two: line 514)

3.6.2 Trying to be 'normal'

For many participants the stigma they felt was related to a strong desire to be 'normal'.

P: It annoys me, it really annoys me. I hate the word [support]. I dunnae like them saying that on the street makes me stick out like a...makes me noticeable.

(Participant two: line 1198)

P: And another..ooh and another one. If somebody came to me down the office, if there's something from expenses, 'I'm working with [own name] cause he's my service-user'. I'd chuck him out the house, I would, I'd grab a hold of them and chuck them out the house, top, top windae. I'm not a service-user, I'm [own full name]. I'm not a service-user. I hate that word too. They 2 words I hate.(Participant two: line 1212)

Participant two describes an extreme aversion to all words which imply that he needs help with everyday living. The issue of stigma seemed to have more of an impact on those who were previously identified as more able to understand and negotiate the system (participant two, participant three & participant seven). It may be that those clients with greater ability levels are more likely to be able to attempt to fit in within society and to get by without others noticing their difficulties. This may create an additional pressure for this group and leave

them somewhere in limbo of not being able to fit into either normally developing society or with their peer group.

An extract from participant three seems to capture this ambivalence about where he fits in or belongs.

P: Well, I was thinking, if I move, probably [place name], other client-, well it was other, it was other patients like myself

I: *Mmhmm*

P: That's got learning diff-, learning difficulties so...I don't know myself if I want to move in that position

I: *Mmhmm*

P: Myself, or will I keep this house? Mm... go to work and things like that but...(Participant three: line 1033)

Although some participants spoke directly about stigma, others raised it indirectly by seeming to hide behind a 'cloak of competence' (Edgerton, 1993). These participants were hesitant to admit that staff were there to help them.

P: Just ...I'll be honest with you, I can do anything, I can do everything. Only thing I cannae do is read my bills, and read my letters.

I: *Right*

P: And I don't want to learn to read and write. If I do, I'm learning on the computer myself, I'm no wantin someone to come along and do it for me.

I: *Right*

P: Cause I willnae I'm just not interested, I'll no be interested, and it's me, that's just me. (Participant two: line 1276)

This was also reflected in the field notes following some of the interviews.

Says 'I dunnae ken' a lot – as if he is worried about giving a stupid answer? Issue with not wanting to appear incompetent. Issue with this client group generally? Afraid to express their views in case they are 'wrong'? (Researcher's field notes, 10/12/10)

This resistance to admitting difficulties and receiving help to overcome them is likely to be another issue holding up participants' progress. Within the field notes it appeared that some participants had learnt to cover up their difficulties in various ways and that at times this was not picked up by staff.

Apparently a genius with rhyming off bus timetables and staff were keen to bring this skill up. When I was there he tried to read the bus times and got this wrong a couple of times but glossed over it and staff didn't seem to notice. Rote learned but can't follow timetables? Is this why he rote learned the times? I wondered if his ability may be being considerably overestimated at times. (Researcher's field notes, 29/10/10)

Similarly the issues with regard to lack of clarity may be exacerbated if individuals are reluctant to admit a lack of knowledge or understanding around certain aspects of their care.

Spoke to [senior staff member] on the phone, says '[...] I says, aye, it's about this time to myself. I was...I'm a bit confused with staff and that'. He says, 'Right, staff are there to keep you safe' and things like that. I went, 'Aye, right, right, right, aye'. That's about it.(Participant three: line 1508)

This may mean that participants continue to rely on staff support rather than admitting difficulties and beginning to learn to take on responsibilities themselves.

In contrast participant seven seemed more able to admit his deficits. This admission, and perhaps the loss of shame which comes with it, seemed to be part of participant seven's empowerment and ability to move forward.

I: And did you write it out or who wrote it out?

P: Eh, I got somebody to write it out, em... and somebody wrote it out and I did it on the computer, eh, got them to check it before I printed it off. (Participant seven: line 45)

Concerns about being normal also created a barrier to developing new relationships, as some participants wanted to distance themselves from other 'service users'. Participant two for example expresses his dissatisfaction at the possibility of a core house being set-up near his flat and other service users moving into the area. This is despite the fact that his staff support could begin to be gradually decreased if there was a core house in the area.

P: I no want that noo, cause I'm no wanting people like..., I just don't want them pushing, cramping all round me cause I'm no wantin' nothing to do with anybody else

I: Right so you want to stay separate-

P: I want-

I: -from the other clients?

P: I'm wantin' to be kept a secret. (Participant two: line 371)

Those who were more willing to interact with individuals in similar situations to themselves seemed to have more in the way of a social circle.

I: So do you see the other service users sometimes?

P: Yeah.

I: How often is that?

P: Eh, once a week or something. All at different times and that. Em, I don't see [name] very often. 'Cause he's in his house all the time.

I: Right. Are there some that you're quite friendly with?

P: Yeah. (Participant eight: line 270)

These accounts allude to the fact that acceptance of difficulties is needed to overcome them.

3.7 Summary of results

An ambivalence towards staff support appeared to pervade the data set as a whole.

It's just...sometimes I feel like eh...I could do without them, and other days I'm no wantin' them, and other days I do want them. And some days I feel like I've just done enough time, being in prison and all this crap ya ken? I've just done enough time, being in here and...I just feel like I've done enough. (Pilot participant: line 824)

Exploring the superordinate themes in detail it is clear to see why this ambivalence is present within the data. The role of staff support within this rehabilitation model seems one of protection and restriction instead of empowerment. This protection is something participants seemed to appreciate at times and the staff team also formed a ready-made social network. The restrictive side to staff support was, however, resented by participants and ultimately the system was not experienced for most as providing the sense of rehabilitation it set out to.

4 Discussion

4.1 Summary of findings

Five main themes emerged from the data: A taste of freedom; Not having control; Getting control back; Loneliness; and Feeling like a service user.

'A taste of freedom' related to the expanded choices and independence offered by community living. The majority of participants, having previously lived in hospital, were used to a more restricted environment and the limits this brought. Community living seemed to open their eyes to the potential for a different kind of life. Some, however, had begun to recognise that there were limits to this freedom and this seemed to bring with it a sense of frustration, as though they were living in a *bigger* box, rather than having escaped the confines altogether.

Control emerged as a central theme, as in previous ward-based research (Hinsby & Baker, 2004). 'Not having control' described participants' sense of disempowerment within the system. There was a general feeling that the structure of the community model favoured the welfare of staff over clients and there was a lack of clarity over the role of staff, the boundaries, and, importantly, how to move on. This feeling of disempowerment was not true for all participants though, and one in particular (participant seven) seemed to be able to benefit from the model rather than seeing it as a restriction. His case was interesting as it was so contrary to other accounts and as it provided an example of how, or perhaps more importantly *with whom*, the system could work. 'Getting control back' encompassed different strategies used by participants to regain feelings of control over their situation either proactively, which showed the possibility of positive, empowering control; passively; or by making the decision to give up and accept things as they were.

'Loneliness' described participants' feelings of isolation generally, due to a limited social network and unstable relationships with family. This was

exacerbated by difficulties in forming and maintaining relationships in the presence of staff members. This isolation meant that a sense of companionship was often formed with members of the staff team, alleviating loneliness in the short-term, but ultimately perpetuating it. Again there were exceptions to this; participant 8, for example, described relationships with other men living in the same accommodation in similar circumstances which suggested a more developed social network in his case.

'Feeling like a service user' was another theme raised by half of the participants in the current study. For some this issue emerged as an overt discussion about feeling stigmatised within the community. More commonly, however, feelings of stigma surfaced covertly in participant accounts as a 'cloak of competence'. Edgerton (1993) used this term to describe the way in which people with a LD attempt to hide their 'incompetency' following integration into the community. In the current study participants seemed to be employing this technique both within the interview itself and, from their accounts, in their interactions with staff. Ironically, maintaining this 'cloak' appeared to be another barrier to gaining independence as it caused participants to avoid admissions about their lack of understanding. This prevented them from seeking further clarity about aspects of their care and engaging in building skills which would lead to greater independence.

Ambivalence towards staff support was evidenced across themes. Support appeared to be viewed by participants as simultaneously protective and restrictive, rather than empowering. As participants described a need for this protection it was welcomed at times but ultimately led to a vicious cycle of dependency on support. This style of support also resulted in a lack of opportunity to develop self-management skills, maintaining this pattern of dependency and leaving participants feeling disempowered. As a consequence

of this, many participants failed to appreciate the rehabilitative aspects of supported living and instead experienced staff support as a form of policing.

The implications of these findings, in terms of the rehabilitative value of the current model, are discussed below, with suggestions for improvement.

4.2 Implications for the community rehabilitation model

4.2.1 A culture of external control

From participant accounts, one of the major flaws of this model is that it exerts a high level of external control, similar to findings within an LD population subject to compulsory care in hospital (McNally *et al.*, 2007). This sense of external control was related to: the staff members' role as protector/restrictor; participants' lack of clarity in relation to expectations of support and how to progress; and the power imbalance between staff and participants. This left participants feeling that rehabilitation was being done *to* them rather than *with* them.

Support staff were perceived as gatekeepers (whether advertently or inadvertently), who could restrict access to certain things and use punitive measures when undesirable behaviour was shown. The overuse of restrictive and punitive control and the limited use of other strategies, such as de-escalation, have been noted in other secure and forensic environments (Duxbury, 2002; Hinsby & Baker, 2004). It is worth considering the message this type of control sends to clients about themselves or their behaviour. For example, they may perceive themselves as 'out of control' or someone that cannot be negotiated with. In addition, by using these strategies, staff members model the use of external control, implying that they themselves are unable to manage the situation without resorting to restrictive methods. Again this concurs with other studies which suggest that this type of management is due to staff members' anxiety about their ability to cope with the situation (Hinsby & Baker, 2004).

The use of punishment to address challenging behaviour was a particularly worrying aspect given the historical move away from this strategy (e.g. LaVigna

& Donnellan, 1986). Aside from the limited effectiveness of punishment on behaviour, this has extremely negative implications for both the clients' quality of life and their relationship with staff members.

4.2.1.1 Implications for risk management

The majority of participants were unclear about how to begin to self-manage and reduce staff input and, in any case, did not seem to feel confident in their ability to do this.

Descriptions of their own behaviour management techniques echoed these notions of external control, for example when they discussed the use of medication to regulate emotions. Their risk management strategies were similar; participants accounts suggested risk could only be controlled by: use of constant staff supervision; complete avoidance of all risky situations; or achieving complete control over all risky thoughts and feelings. The same type of external strategising was noted within McNally *et al.* (2007). Continued reliance on these external mechanisms as the sole strategy for managing their emotions, and their risk more generally, may make it very difficult for these clients to progress towards self-management, or even to feel that this is an achievable goal. These accounts paint the system as accomplishing the opposite of what it set out to achieve. It tends to exert external control, leaving those within it feeling less and less able to take on their own risk management, trapping them in the role of dependent.

Overreliance on staff is not a difficulty unique to this service; it has also been noted in similar models with other types of vulnerable clients who receive intensive support. Lewis (1990) discusses parallel issues in chronic mental health clients who are supported by assertive outreach teams in the community,

Do ACT [assertive community treatment] clients come to rely on staff for help with problems in living? If they do – what are the trade-offs as they become increasingly dependent on the emerging world of private agencies that perform public functions?...What is gained and what is lost as family, friends and church are replaced by these kindly professionals who shape life chances for citizens with a severe mental illness? (Lewis, 1990, p. 925-6)

Lewis (1990) voices concern that the wider repercussions of breeding reliance on professionals in this way are not well understood.

Participants described a lack of control in relation to their care plan feeling that their level of risk was judged by others, and their progress was dependent on this judgement. This perceived lack of self-determination may lead clients to employ a 'head down' type approach, learning to conceal anything that could hinder their progress. This form of subtle non-compliance, or 'playing the game', has also been noted in another study at service user views of compulsory treatment in the community (Gault, 2009, p.509). If participants respond in this way to restrictions they may increase their risk as early warning signs of recidivism will be missed (Pithers *et al.*, 1983). Long-term, therefore, this model of care could be setting up permanent disengagement from services, ultimately increasing the risk of deterioration in mental health and recidivism (Dixon *et al.*, 2009).

Messages and modelling of restrictive control are not helpful within a rehabilitation setting. A more appropriate and achievable aim is the development of self-management techniques which will empower the individual to cope with their risk-related thoughts and feelings without them manifesting as behaviour; there is an explicit acknowledgement that the thoughts and feelings themselves may always remain (Johnston *et al.*, 1997). Not only is a strategy of complete control likely to result in failure for the client, and

further feelings of helplessness, but attempts to achieve this level of control over thought processes can indirectly lead to further offending (Ward & Hudson, 2000).

4.2.1.2 Implications for forming a new self-identity

The restrictive style of the current model seems to make it difficult for clients to separate themselves from their past and create a new self-identity, beyond their label as an offender (Haaven *et al.*, 1990; Laub & Sampson, 2003). The restrictions in their lives could be viewed as a constant reminder of their past.

Some participants appeared preoccupied with concerns over their immediate future (i.e. when they would begin to reduce staff support) and this created a barrier to thinking about their wider hopes for their future. Without these longer term goals and aspirations in mind it may be difficult to move forward, as there is nothing to move forward to.

(...) that the future also *now* exists in the person in the form of ideals, hopes, goals, unrealised potentials (...). One for who no future exists is reduced to the concrete, to hopelessness, to emptiness. For him time must be endlessly "filled". Striving, the usual organiser of most activity, when lost, leaves the person unorganised and unintegrated. (Maslow, 1998, p.202)

From participant accounts, the current rehabilitation model appears to promote the first two levels of Maslow's hierarchy (fulfilling basic needs and the need for security/stability), but does not go on to adequately support or promote any of the higher level needs described, halting the client's progress at these early stages. Without meeting these higher level needs the individual never reaches a state of self-actualisation (Maslow, 1998) which may help to promote their rehabilitation by decreasing preoccupation with fulfilment of their own needs and aiding the formation of a new identity.

Maslow emphasises how embarking upon the journey of personal growth can be an intimidating experience and requires 'protection, permission and encouragement from the environment' (1998, p.196). It may be that those who succeed in this system, like participant seven, can facilitate their own climb up the levels, for example with more ability, confidence and social skills, but that individuals who cannot remain at these basic levels.

4.2.2 Continued social isolation

One of the main themes within the current study was loneliness, similar to findings by McNally *et al.* (2007). This initial isolation is likely to be due to a number of factors. People with LD often have impoverished social networks (Robertson *et al.*, 2001) and the unstable family relationships participants described are also common in offending populations (Farrington, 1995; McCormack, 2002).

This isolation seemed to be exacerbated by participants' perceptions of support as a social barrier, as has been noted in other supported environments for people with LD (Hollomotz, 2009). For many participants this either deterred them engaging in social activities or from pursuing relationships whilst in social situations. This created a situation where the individual's already limited social network was disrupted or hindered further due to presence of support staff. Support therefore seemed to increase social isolation rather than decrease it.

In addition, a number of participants did not return to live in their previous communities either due to practical housing issues or as a consequence of targeting within their old community. This difficulty with integration when individuals are placed within communities where they lack even the beginnings of a social network has been noted for other groups, for example those with mental health difficulties and the homeless (Goodwin, 1997).

4.2.3 Stigma as an obstacle to community integration

As Cummins and Lau (2003) have discussed, community integration is not as straightforward as it first appears. Even with a generic LD population, without some of the psychological and interactional difficulties of the study population, O'Brien (1987) discussed the achievability of community *participation*, as opposed to simply community *presence*. By this he meant that although people with a LD could occupy the same social spaces as others, their interaction with this environment was qualitatively different, leaving them with ongoing feelings of social isolation and exclusion.

Participants expressed difficulties relating to their perceptions of stigma within the community. Their accounts gave the impression of moving from one stigma into another: they are extracted from the criminal justice system and the label of 'offender' but placed into a support system to which some attached an even greater stigma.

Participant accounts were highly reminiscent of the 'cloak of competence' phenomena noted within Edgerton's study (e.g. Edgerton, 1993). Edgerton used observational studies and interviews to look in-depth at the challenges faced by people with LD who were reintegrating into the community following de-institutionalisation. As in Edgerton's work participants in the current study attempted to mask their difficulties. It was unclear whether this was a product of the general stigma faced by the intellectually disabled population or whether living among the normally developing population increased pressure to hide deficits, in order to fit in.

Stigma was also a significant factor for these participants in forming relationships within the community. They were reluctant to develop relationships due to the fact that they would ultimately have to explain the presence of staff members; this would mean either an admission that they required help with daily living or that they were considered a risk to the public.

This concept of burden is an ongoing issue during reintegration (Barnham & Hayward, 1995).

In addition, there was a sense that these participants, especially those who were more able, did not have a shared sense of identity with any specific group. The two participants who described more social interaction appeared more accepting of a learning disabled peer group. These participants spent time with others in the same supported housing blocks, which formed ready-made communities. Two further participants also spoke positively about hospital living; compared to life in the community, this more restricted environment increased opportunities to fulfil roles, gain status, and interact with others. For both these sets of participants contained environments, with the availability of peers, seemed to foster a greater sense of belonging which they struggled to achieve in the wider community.

McArdle (1998) suggests that although communities can be thought of as geographical areas they can also refer simply to groups of people with shared interests and shared concerns. It may be necessary to think more flexibly about how 'community' applies for this client group and how to create opportunities for this sense of belonging.

4.2.4 Staff-client relationships

Although the set-up of the community model itself appeared to be the main cause of frustration for participants, the delicate power balance of staff-client relationships was, at times, a concern.

One complicating factor is that participants' homes double as staff workplaces. This creates a tension between the clients' needs and those of the staff team. Mansell (2010) comments on similar difficulties of the competing demands of the LD care system, many of which, including the rights of workers, are directly in contrast to client-centred working. He argues that this is something that needs

to be actively acknowledged and redressed. Mansell suggests that the solution is to have people in their own homes with support as and when they require it, on their terms. The question is how this model can be applied for people who present a risk to the public in order to give them a sense of ownership and empowerment while still managing risk.

Participants mentioned specific positive relationships with certain staff members, as well as specific seniors or managers. These relationships were not, however, always seen as positive. Seniors and care provider managers were, in some cases, seen to be aligned with the staff team rather than providing an independent channel through which the service user could raise issues. Multi-disciplinary professionals may be thought of as another channel through which the service user could raise issues but this was not mentioned by any participants in the current study. It may be that these individuals do not always have consistent contact with another professional or, similar to seniors and managers, other professionals may be seen as affiliated with the support team meaning they are not considered impartial.

4.3 Towards a more effective model

4.3.1 Achieving clarity

Part of the disempowerment participants expressed in the current study was related to a lack of understanding about various aspects of the system they inhabited. This lack of clarity has been commented on previously within the literature in relation to both psychiatric and learning disabled patients who have been admitted to hospital (McNally *et al.*, 2007). It was unclear in the current study whether this was due to: a lack of explanation about these aspects; the information not having been made accessible to the client group; or whether this reflected a general lack of clarity which goes beyond the clients themselves.

4.3.1.1 The role of support staff

It seems clear from the findings that clarification is needed regarding the remit of staff teams. This would be beneficial in terms of clients' understanding of what to expect from staff members. When one of the functions of the relationship is supervisory in nature, Trotter & Evans (2010) discuss the importance of role clarification. This covers a number of issues: clarification of boundaries and confidentiality; the powers of the supervisor to implement consequences following breach behaviours; and the negotiation of the dual role as both an enforcer of social control and a means of rehabilitation.

In addition it is important that staff teams themselves and other professionals are clear about the boundaries of this role. It is acknowledged that these boundaries are not always clear cut and this indicates the need for ongoing support and discussion of these issues, perhaps within a regular multi-disciplinary forum.

4.3.1.2 What does 'moving on' mean?

Participants also expressed confusion and frustration about how to move on. Perhaps part of this difficulty was in being clear about, not only how to move on, but what moving on actual means in practice. Compulsory care orders do have stipulated powers but these are quite general and open to interpretation, for example, that the individual must accept certain professionals into their home, should attend certain appointments, and should reside at a certain residence (MHA, 2003, 64(4)). It may be that the system itself lacks clarity about how and when clients should move on.

This introduces a number of questions, for example, whether or not those within the system (e.g. care providers, professionals) are clear at the beginning of a community order what the end goal is. Many of these clients may never be able to live completely independently, regardless of risk, due to their need for

support with daily living skills. For others it is possible that self-management strategies will only assist the individual to reach a certain level and they will therefore remain in need of some form of risk management structure.

There is no obligation on professionals to provide clients with information about the likely duration of their order. Although this may not be known at the commencement of the order, it may still be beneficial to inform the client of the factors which are likely to increase or decrease the duration. It is unclear whether clients are aware of the goals of their care, the markers of progression, and the likely outcome. Perhaps an even more pertinent question is - are professionals clear?

Clear care pathways which outline the individual goals and time frames for gradual progression on the community order should be shared with clients. This is to make clear what is required of the individual in order to progress, as well as how to achieve this, but also to make this a tangible reality, enhancing hope for the future.

It may be argued that it is unclear at the outset how long an individual will need to remain on their order but if this is a completely unknown variable it effectively introduces the possibility that the order may be indefinite. For this community model to be considered as rehabilitation, there must be a continued possibility of a next step, a progression. Without this the system becomes nothing more than a holding mechanism, akin to prison.

4.3.1.3 Addressing high expectations

Participants who reported more success within the community model were those with more understanding and awareness of the system around them, and who were able to both identify and assertively address their own needs. Participant seven was the only participant who seemed to achieve this fully. The obvious issue here is whether this participant's skills are typical or atypical of

individuals within this client group. The fact that this participant was the only one of ten who seemed to feel empowered within this set-up implies that he is more the exception than the rule. The small sample size of this study, however, makes it difficult to draw any specific conclusions.

Taking what we know from the literature, a typical individual with LD and forensic needs would be expected to present with high levels of mental health difficulty, insecure attachment patterns, communication difficulties, high levels of acquiescence and low levels of assertiveness (Lindsay, 2002; McCormack *et al.*, 2002; Hobson & Rose, 2008). Taken together these factors seem to indicate that clients who would have the abilities necessary to drive forward their own care would be atypical within this population. With so many additional difficulties it would be unsurprising if individuals within this group had difficulty with rehabilitation. Indeed, people with LD are often found to be those who remain in secure settings longest and are least likely to be discharged (Johnston & Halstead, 2000).

This raises a concern that the current community rehabilitation model may expect too much from service users. Steptoe *et al.* (2006) have demonstrated that integration does not spontaneously occur within this population; even when those with sexual offending histories had opportunities for social contact they tended not to take them.

It is unclear what happens to those who do not make gains within this model. Again, Lewis (1990) asked similar questions of his mental health population.

Which kinds of clients do well under this shadow government and which are shunted aside because they are too hard to handle or unresponsive? (p.926)

The reciprocity principle on which the new MHA 2003 is based states that where individuals are subject to compulsory care by law, there is a duty to provide them with appropriate rehabilitation opportunities. This leads to another issue

of whether or not this form of care is providing people the support they need to progress. It is clear that this group will need more than just opportunities to develop relationships and, potentially, to meet other basic needs as well. In the GLM Ward specifically discusses lack of skills as one of the barriers to meeting primary needs, and a route into anti-social behaviour (e.g. Ward & Brown, 2004; Ward & Mann, 2004).

There may be significant difficulties in identifying when an individual from this group has been successfully 'rehabilitated' due to unrealistic expectations. Similar issues have been raised within services that monitor parenting practices with individuals with a LD. As these individuals are monitored, the expectations of what they should achieve are heightened. Normal errors which would be expected, and could be learnt from, are either prevented from occurring or are judged in an overly harsh manner (Ward & Tarleton, 2007). Not only might supervision in itself raise expectations but it is also important to identify the appropriate group for comparison. If directly comparing what an individual with LD and a forensic background might be capable of to a non-disabled, non-offending counterpart then the bar is set too high, and failure to meet these standards seems likely.

4.3.2 Helping clients to be heard

The system of compulsory care, as demonstrated by participant accounts, is fraught with challenges. Participants described feeling more empowered when there was an avenue through which to raise concerns, for example through the Care Programme Approach (CPA) process or via independent advocacy services. It is therefore vital that clients have somewhere to discuss these issues and clarify boundaries to keep the system as balanced as possible. Clarity from the beginning is important but unique concerns will emerge in individual cases, emphasising the need for an appropriate forum to raise these issues.

This is true of any group subject to compulsory care but especially in the case of these individuals who are at a further disadvantage in terms of social understanding and ability to communicate their needs. Additionally past environments, which may act as a benchmark for their treatment by others, may be skewed by previous maltreatment or victimization (Emerson *et al.*, 2005).

The CPA is used within multidisciplinary working for planning and reviewing care for complex clients, and actively involves the clients themselves in the process (Department of Health, 2008). In the current study CPA emerged as a means by which requests could be made and progress could happen. Advocacy groups also appeared to be a valued and impartial channel through which individuals could express their views and gain a sense of empowerment. Some positive, trusting relationships also existed between participants and members of their team, and between participants and seniors or managers.

All these channels are worth strengthening and making more consistent within the community model. Advocacy groups, in particular, seem an important area to build on. As well as being a forum to raise issues, they provide an opportunity where commonalities can be found creating a sense of shared identity. Goodley refers to the functions of these groups as multi-faceted in that they promote 'friendship-making (interpersonal), rule-challenging (social), and label-checking (political)'. (Goodley, 2005, p.338).

Again there is an issue of which types of participants possess the motivation and understanding to take advantage of any such advocacy opportunities. One participant mentioned having had an advocate previously but letting this lapse as he was uncertain of the individual's function. Again this emphasises the fact that service users require an understanding of what these channels are *for*, as well as how to access them, before they can be a useful tool.

Some participants had involvement in other initiatives which lent them a voice, for example, taking part in interviews for new staff, and this appeared to be a positive step. From participant accounts, however, further steps are required to make this meaningful to the clients, for example, choosing members of their own team rather than those joining the service.

4.3.3 Empowering support staff

Participant accounts in the current study appeared to indicate a lack of promotion of self-management skills. As the main contact point for clients, staff members are the group expected to support the development of these skills, however, the training and skills they themselves bring to the role may not be sufficient for this. In addition, the promotion of messages of internal control will only be possible if staff members feel they have the skills to manage clients appropriately. Current literature suggests frontline staff within forensic services do not always have these feelings of self-efficacy, and that this lack of confidence can lead to the implementation of more stringent and staff-led forms of risk management (Hinsby & Baker, 2004).

Staff members working within forensic services are regarded as specialised, but the premise on which this is based is questionable (Martin, 2001). Most studies recommend that further training and professional development is needed in order to manage the roles required by a forensic support service (Meehan *et al.*, 2006).

Empowerment of staff through training and supervision may therefore be fundamental in, not only helping them to achieve clarity over their role, but also in increasing their confidence to carry out this role. Gaining knowledge of the client's overarching treatment goals, as well as receiving training on how these are to be achieved, may illuminate the reasons for promoting self-management.

In addition, participant accounts reflected the potential for staff-client relationships to become non-therapeutic at times. At least partly this seemed to reflect a failure, on the part of the staff member, to keep in mind the power imbalance within the staff-client relationship. Martin (2001) writes that forensic staff, in the hospital settings to which his paper refers, 'will remain a sub-speciality of psychiatric nursing until what is distinct and *therapeutic* about the practice is articulated' (p.25, emphasis added). Martin calls for a return to the consideration of the relationship between staff and patients as the crucial element on which the remainder of the service is built.

Similarly, empowering staff members through further training and supervision could help them to maintain a therapeutic stance towards the client, and ensure they keep an acute awareness of the delicate power imbalance implicit in their role.

4.3.3.1 Awareness of overarching treatment goals

Although staff opinions were not formally recorded, issues were raised by staff members informally during the research process. One staff member commented that it was helpful to experience being a key-worker as this meant involvement in CPAs and a chance to become part of the 'bigger picture' of the individual's care.

As staff teams are mainly involved with the day-to-day management of individuals, there is a risk they could become somewhat removed from the overarching goals of care. Perhaps if staff were included in more detailed consultations relating to the broader goals of care planning they would feel more empowered to support and progress individuals rather than manage and hold them. Broader multi-disciplinary discussion of these issues, and multi-disciplinary team decisions, could help to diffuse the responsibility staff teams may feel as those on the front-line.

One way in which this could be achieved is through shared formulation meetings with the client's core team similar to those currently applied within challenging behaviour services (Ingham *et al.*, 2008; Ingham 2011). Members of the team, and in particular frontline staff, serve as the experts in relation to the client's background, behaviour, and needs, while staff with psychology training facilitate and shape this information according to a psychological framework, to produce a shared understanding of the client's difficulties. This understanding draws out the client's strengths and resources, giving a fuller picture of the individual as a whole instead of focusing solely on the risk they present. These types of meetings, if regularly applied, could also assist in the clarification of goals, co-ordination of care, and improvement of outcomes, both in terms of staff attitudes and client response (Ingham 2011).

4.3.3.2 Increasing staff skills

Integration of the current findings with empirical evidence suggests that a lack of confidence may cause staff members to adopt more restrictive approaches (Hinsby & Baker, 2009). One area in which staff teams may lack confidence is risk assessment and management which may cause them to adopt more risk-averse strategies at times (i.e. 'better safe than sorry'). Robinson & Reed (1996) worryingly found that nursing staff made more use of assessment-based tools for predicting risk in general psychiatry than they did on forensic wards, where general opinion of the patients' risk seemed to determine their level of supervision.

General training to provide further clarity on these processes may be beneficial, as well as thorough consultation with members of the multi-disciplinary team about the risks individual clients present and how these should be managed. Risk assessment and management should always be carried out in a multi-disciplinary environment which will ensure opinions of all core team members are taken into account and that responsibility for this is shared (Doyle & Dolan,

2002). Careful multi-disciplinary risk assessment and management should help to fully clarify the specific risks, including the likelihood in certain situations, the seriousness if this did occur, and how best to manage this (HCR-20; Douglas *et al.*, 1999). This should increase staff members' confidence in delivering care according to these multi-disciplinary plans and promoting positive risk-taking strategies.

For example, certain positive risk-taking episodes, which will benefit risk management in the long-term, may at first seem counter-intuitive. If an individual has sexually offended against children this does not necessarily mean they should never be in situations where children are present. In fact, it might mean the opposite, that their presence in these situations is necessary to gauge their risk and learn strategies to manage this. If the consensus is that individuals cannot be managed in a situation where a member of their victim group is present then serious consideration should be given to whether a community placement is appropriate.

Other skills such as pro-social modelling and reinforcement, and joint problem-solving have been shown to improve relationships between clients and the professionals involved in their risk management (Trotter & Evans, 2010). If these skills are valued by clients and are useful in terms of rehabilitation then it is important to ensure staff teams feel confident in applying these.

Positive approaches need to become more than just a rhetoric. Staff training and recruitment should place less emphasis on risk and more on promoting abilities, including self-management, and fostering ideas of hope.

4.3.3.3 Making relationships more therapeutic

The literature is now moving beyond 'what works' to more complex questions of why it works, and *with whom* it works (MacNeill *et al.*, 2010). The importance of personal style and approach in the delivery of not only rehabilitation

interventions but regular statutory supervision, is becoming a recognised factor affecting outcome (Trotter & Evans, 2010). Much of the recent research examining personal factors within offender supervision focuses on probation officers within mainstream services, but the principles can be applied to support staff in this type of setting due to the significant overlap of the roles. Beyond the individual relationship, rapport with the staff team can also have an impact on how the care package as a whole is experienced (Reinders, 2010).

Trotter & Evans (2010) emphasise the importance of a therapeutic relationship between a supervisor and supervisee. MacNeill, (2010) argues that within rehabilitation settings, when we are effectively asking people to change their moral values to those more similar to ours, change is only possible within a relationship which fosters respect and trust.

Therapist factors, for example empathy, positive reinforcement and willingness to develop shared goals, are regularly discussed as one of the variables affecting treatment with sexual offenders (e.g. Marshall *et al.*, 2003; Ward & Brown, 2004) but this seems less valued in direct care staff at present. Gildberg *et al.* (2010) make the point that personal characteristics such as warmth, empathy, and genuineness are written about explicitly in Danish textbooks on mental health nursing as having a positive effect on the staff-patient relationship. Although these same characteristics appear to also be valued in British studies (e.g. Clarkson *et al.*, 2009) they are less explicitly discussed within services. Some of the characteristics which emerge as helpful in building rapport are somewhat straightforward or obvious but it is perhaps time that the implicit was made explicit within training and emphasis was placed more heavily on recruiting and training frontline staff with these aspects in mind.

Providing more psychological input to staff, in terms of general training, consultancy on individual case management, or supervision, may be beneficial in creating and maintaining a therapeutic relationship with clients (Arthur, 1999). Schafer & Peternelj (2003) noted in their study that the manner in which messages were delivered was more important to clients than what was actually being said, thus emphasising the relevance of basic concepts such as body language and tone of voice.

Another factor raised by service users as an important means of improving relationships is flexibility of approach, as it demonstrates that they are more than 'just a number' (MacNeill, 2010). Hinsby & Baker (2004) found that clients rated the relationship more positively if the member of staff spent extra time with them, displayed warmth, and showed flexibility in the delivery of rules. This is important empirical evidence to employ within clinical practice.

4.3.3.4 Staff supervision and support

Negative behaviours displayed by staff members were noted in the current study and have been noted by LD clients in forensic services previously. For example service users within LD forensic services reported staff being deliberately unhelpful, 'winding' them up, being arrogant or intimidating, and having a short-temper (Clarkson *et al.*, 2009). Some of these negative behaviours may be a consequence of burnout, which is expected within a staff group with higher levels of role conflict (Melchior *et al.*, 1997).

When forensic nursing staff are provided with additional training on psycho-education and psycho-social principles their levels of stress decrease and they have a more positive orientation towards the client (Ewers *et al.*, 2002). Although this is a positive finding, training sessions alone are unlikely to maintain this. It is considered essential that frontline staff receive appropriate support and clinical supervision (Coffey & Coleman, 2001). This is especially true in forensic

areas where the challenges of their dual roles should be explicitly discussed and addressed.

Supervision should go beyond line management, recognising the difficulties inherent in this role and the likely by-products of high stress levels and burnout. It should also focus on helping staff to reflect on their own backgrounds and attachment styles, which, if not brought into their awareness, may well have an impact on their style of support and ability to act as effective role-models for clients (Schuengel *et al.*, 2010). For staff members with less secure attachment styles, help-seeking behaviour may also be reduced leading to further difficulties in an already stressful profession (Hawkins *et al.*, 2006). It is therefore important that supervision is an expected and required aspect of the role.

Similarly, supervision could ensure regular checks to maintain awareness of the (expected) power imbalance between staff and clients (Conway, 1994). This must be the responsibility of staff at the upper end of this imbalance. Boundaries will inevitably become blurred at times and, again, supervision is the opportunity to monitor and address this (Coffey & Coleman, 2001). This blurring of boundaries can also emanate from the behaviour of service users, for example Clarkson *et al.* (2009) noted that clients can seek nurturance from staff causing interactions to become more similar to that of parent and child. Again, this should be an expected consequence of the formation of close relationships with attachment disordered individuals, as this client group are known to be (McCormack *et al.*, 2002). Recognition of this and reflection on the interaction could help to redress some of these issues.

In light of the types of issues which may be pertinent with this client group it may be that supervision delivered by psychologists, or other professionals trained within in this field, would be logical.

4.3.3.5 Use of more environmental control

It may be that the use of increased environmental control could also improve staff-client relationships by decreasing one-to-one contact, reducing interpersonal tensions, and reducing the burden placed on staff as the main source of managing risk.

Although intuitively increasing physical restraints may be thought to increase clients' feelings of lack of control, this did not seem to be the case in the current study. Participants did not mention constraints in their environment (e.g. alarmed doors) as a source of difficulty. Those who lived within an environment where smart technology was employed mentioned this only in passing and did not seem perturbed by it. It may be that, counter-intuitively, a more physically controlled environment actually leads to feelings of greater freedom. These findings are very tentative but they indicate that the option of increased physical restrictions and technological monitoring may be worth exploring.

4.3.4 Addressing stigma

There may be some merit in addressing community integration indirectly through addressing stigma. Participant accounts of stigma in the current study appeared to be based on their own perceptions rather than how they were actually treated within the community. This has been noted in other studies as well (e.g. Gerber *et al.*, 2003). There is little doubt that there are ongoing difficulties with societal attitudes but much of the difficulty expressed in the current study appeared to stem from individuals' internalisation of this stigma. As so much of stigma is associated with shame and hidden deficits (Matthews & Harrington, 2000) it may be that exploring these issues with clients more explicitly would lead to a reduction in their impact.

It appeared that participant seven, who coped well within this model, did so due, in part, to his willingness to admit difficulties and ask for support when

necessary. Similarly participants one and eight had access to a social network as they were willing to socialise with other service users and view themselves as part of this group. It is this level of self-acceptance that seems to be important.

There is scope for improvement even by addressing the attitudes of staff teams and other professionals who can feed into stigma by promoting 'normality' and failing to bring up difficulties for fear of embarrassing the individual or causing feelings of inadequacy (Craig *et al.*, 2002). If those around the client can be more open about the individual's difficulties, this may encourage them to do similarly. There should also be consideration of the wider messages given to these clients regarding who they *should* be incorporating into their social network and whether or not normalisation has gone too far when it moves people away from peers by enforcing inclusion in this way.

4.4 Limitations of the current study

There were various limitations to the current study. Speech difficulties were present in almost all the participants, emphasising general difficulties with communication for this group. This did present a barrier, however, it was for the most part overcome by spending more time with the participant pre-interview and taking brief notes during the interview to serve as reminders. The use of communication aids (photographs, daily planners) were helpful in the current study as they could be used to supplement verbal language.

Expressive language difficulties did not seem to be an issue for the majority of participants, echoing sentiments from other researchers in the field (Yacob & Hall, 2008). There may be unnecessary caution around interviewing subjects with LD and worries over the richness of the data produced (Yacob & Hall, 2008). It was clear, in fact, that participants were able to reflect on their

experience and express their views and, importantly, that most had not had this opportunity previously.

Staff interference was a difficulty in some cases and resulted in the interviews being conducted in less preferable settings and without the level of privacy that would have been desirable to put the participant at ease. This may have had implications in terms of the level of openness of some of the interviews. In several transcripts, for example, staff members could be heard in the background and on more than one occasion the interview had to be suspended in order to address this. Considering the topic under discussion this may have meant that some participants did not feel able to be completely honest about their views.

There may have been other issues which held participants back during interview. Hollway & Jefferson (2000) talk about the 'defended subject' (p.59), by which they mean individuals, in general, are likely to provide self-defensive accounts of their lives as this is how they choose to see themselves. This can result in a mismatch between overt speech and covert cognitions or emotions. Defended-ness may have been a factor for some of the participants, especially in light of some of the findings around stigma and the need to present a competent self.

In addition, some of the participants made comments during interview that suggested they believed the researcher may have been able to help them in some way, which may have influenced the way in which they presented themselves within their narrative. Two participants openly asked for help: one for help getting further support; and one with help getting prescribed medication. Despite efforts by the researcher to be clear about their role, participants may have identified them as a potentially powerful figure connected to the system

they were in (Walmsley, 2004). This, in turn, may have caused them to withhold certain potentially relevant details, for example very few participants mentioned their past offending directly. These issues, taken together, may have skewed the data somewhat.

It is also important to see the interviewer themselves as a defended subject (Hollway & Jefferson, 2000) who will have shaped, interpreted and presented the data in a certain way according to their own self-defensive beliefs. One of the benefits of IPA, however, is the explicit recognition of this interpretation, and the attempt to separate the voice of the researcher from that of the participants throughout the analysis (Smith *et al.*, 2009).

The overall generalisability of qualitative studies is always limited due to the small number of participants. These findings, however, provide valuable theoretical generalisation, in that they broaden our understanding of some of the issues which may be present for individuals within similar services. For example the current study is highly relevant to other mentally disordered offenders and other mental health patients subject to compulsory care. Some of the issues are undoubtedly relevant for a LD population without forensic issues who nonetheless may have high levels of staff support.

Lastly, IPA recommends that samples are kept as homogenous as possible so that findings can be more readily generalised to that specific group of individuals (Smith *et al.*, 2009). As the current sample was made up of participants from various care providers, with slightly different types of accommodation, varying levels of LD, and differing types of forensic backgrounds, this could be seen as too heterogeneous a sample. It is important to note, however, that these more varied accounts were helpful in drawing out certain factors that seemed to help or hinder participants which are worth

further investigation. For example, some heterogeneity was useful in terms of understanding what type of client might be able to negotiate the system more successfully, and to compare the impact of more environmental restrictions to consistent one-to-one supervision.

4.5 Future research

There is a wealth of future research that would be useful within this area. In terms of further qualitative research, it would be interesting to gauge the views of both professionals and staff members on what the goal of rehabilitation is, perhaps in relation to specific clients or case studies, and compare these to see if there is a clear, consistent view on expected outcomes.

Suggestions have been made here for improving the system but it would be useful to explore from a staff perspective what the difficulties might be in applying these suggestions. It would also be useful to identify what staff members themselves believe are the difficulties within the current system and what would help them within their role.

As previously stated, quantitative and qualitative research methods are best used as a pair. It would be useful if quantitative research could explore some of the ideas discussed here, which would help to generalise the findings. First and foremost it would be important to look at how many clients in Scotland, and perhaps across the UK, with LD and forensic needs are subject to community-based orders. Within this client group, it would be useful to know what the outcomes are, that is, how long individuals are generally subject to this type of order, and what they move onto: informal staff support; relatively independent living; return to secure hospital environments; or something else.

Looking in further detail, it would also be interesting to compare hours of staff contact (both when engaged in activity and when not engaged) and clients'

satisfaction with the care package. Although it was beyond the scope of this study, and may have also jeopardised the anonymity of the participants if elaborated, anecdotal observations were that those with less direct time with staff members were more satisfied with their living arrangements. Interestingly, physical restrictions did not seem to be a significant cause for concern for participants and again, the level of physical restriction and client satisfaction would be interesting to explore. Whether or not levels of satisfaction decrease over time would also be interesting to research, that is, are levels of satisfactions related to the client's appraisal of their *current* living situation or is it entirely based on the hope of moving onto more independent living.

Further research would also be helpful in considering the type of training and supervision which would be most useful for staff members working within forensic LD services, exploring the impact of different types of training and supervision on staff burnout rates, staff turnover, staff-client relationships, and client satisfaction with the service.

It would also be useful to look in more detail at the characteristics that allow certain individuals to succeed and become discharged from their orders and how these characteristics might be promoted in this population.

Another interesting, almost separate, avenue of exploration highlighted by this study was the impact of stigma as a barrier to integration. Additional areas for potential research in this area alone are vast. For example it would be useful to look at the interaction between clients' perceived stigma and their level of community integration (both subjective and objective). Consideration could be given to different types of intervention which may be used to address this issue (e.g. direct psychological integration, indirect intervention via training of multi-disciplinary professionals working with this group, or a wider community education approach). Outcome measures could then be used to gauge whether

or not these interventions have an impact on client self-perception and integration, giving guidance to which to employ.

4.6 Summary and conclusion

Using an IPA approach, the experiences of ten participants with LD and forensic needs subject to compulsory care within the community were explored. Accounts were rich and insightful and allowed poignant conclusions to be drawn about positive opportunities available within the community, but also flaws within the model which may be limiting its effectiveness.

Following the introduction of community-based orders with the implementation of the MHA 2003, which formally came into being in 2005, there has been a need to review the use of these orders with this particular client group. This is especially due to the fact that this legislation was initially meant for use with the so-called 'revolving-door' patient within mental health services, primarily to aid compliance with medication. Learning-disabled clients with forensic needs who require high levels of risk management and social support are a very different client group.

The findings paint a varied picture of the experience of community-based orders from a client perspective. Although participants within the current study reported a number of positives with regard to community-living they also reported some significant issues with the set-up of compulsory community care as it stands. Specifically, clients appeared to experience continued social isolation and described the system as both protecting and restricting them rather than empowering them to self-manage. This depicted the community model as more of a holding mechanism than a rehabilitative tool. If this is the case then the system is actually exacerbating some of the difficulties it is attempting to address.

This is not to say that the community-model does not work but that serious flaws seem to have occurred between ideation and implementation which need to be addressed. Studies such as this one give us the chance to draw out some of these issues in order to explore solutions. It is hoped that through dissemination of these findings the voice of these service users can be translated into clinical practice.

A number of suggestions have been made about how some of the issues within the model can be tackled but further research is needed to explore specific aspects of the community-based model and the clients within it to better understand what would increase the model's viability.

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6 Appendices

6.1 Appendix 1 – Interview guide

Moving on: Community rehabilitation for PWLD and a forensic history

Interview schedule

Version 2

16/5/10

General opener

- Can you tell me a bit about where you are living at the minute (refer to photo prompts if necessary)

Comparisons with past circumstances:

- Before we talk more about things as they are now – can you tell me a bit about where you lived before (hospital, prison, community)?

Insight into daily life (noting the extent to which staff are seen as integral to that or on sidelines):

- Tell me what happens on a normal day for you
-

Focusing on living with staff support:

- What do you think about having staff around?
 - How do you get along with staff?
 - How did you come to have staff?
 - Can you tell me about the first time you remember having staff with you (in your house)?
 - Have your feelings changed over time?
- How often do you see staff?
- Can you tell me about what staff are there to do?
- Can you tell me about a difficult time you have had with staff?
- Can you tell me about a good time you have had with staff?

Hopes for the future (will this happen with staff around or only when further independence from staff is reached?):

- If you could change anything about your life, what would you change?
 - If you could wave a magic wand and have everything exactly the way you wanted – what would be different?
 - What would you need to do for that to happen?

6.2 Appendix 2 – Participant information sheet

6.3 Appendix 3 - Participant consent form

6.4 Appendix 4 – Transcription key

Transcription Guidelines

Based on **King & Horrocks (2010)**

<i>Italics</i>	Italics used to denote emphasis
...	Very short pauses (under 2 seconds) indicated by ellipsis
[2 sec pause]	Longer pauses within square brackets – duration included
'-'	Hyphen denotes an interruption
Then he said 'hello'	Direct speech between single quotes
[incomprehensible]	Inaudible parts placed in square brackets

[laughing] [non verbal] [ironic tone]

Other important aspects of conversation which may convey meaning included in square brackets

6.5 *Appendix 5*

6.5.1 NHS ethical approval

6.5.2 NHS management approval

East of Scotland Research Ethics Service

Tayside Committee on Medical Research Ethics A

Research Ethics Office
TAHSC, Residency Block C
Ninewells Hospital & Medical School
DUNDEE
DD1 9SY

Miss Alana D Davis
Specialist Psychological Practitioner
NHS Fife
Clinical Psychology Dept
Lynebank Hospital, Halbeath Rd
DUNFERMLINE
KY11 4UW

Date: 04 August 2010
Your Ref:
Our Ref: FB/10/S0501/31
Enquiries to: Miss Fiona Bain
Extension: Ninewells extension 32701
Direct Line: 01382 632701
Email: fionabain@nhs.net

Dear Miss Davis

Full title of study: Moving on? People with learning disability and forensic history: views on receiving high levels of staff support as a form rehabilitation in the community
REC reference number: 10/S1401/31

Thank you for your letter of 13 July and email of 02 August 2010. I can confirm the REC has received the documents listed below as evidence of compliance with the approval conditions detailed in our letter dated 01 July 2010. Please note these documents are for information only and have not been reviewed by the committee.

Documents received

The documents received were as follows:

Document	Version	Date
Covering Letter		13 July 2010
Participant Information Sheet	5	09 July 2010
Participant Consent Form: Participant Consent Form*	5	02 August 2010
Participant Consent Form	4	09 July 2010

*it is understood that version 5 of the Consent Form, dated 02 August 2010 will be used as advised by me.

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.



Yours sincerely



Miss Fiona Bain
Committee Co-ordinator

Copy to: Gemma Watson, University of Edinburgh
NHS Fife R&D office



Miss Alana Davis
Specialist Psychological Practitioner
Clinical Psychology Dept
Lynebank Hospital
DUNFERMLINE

Medical Director, Primary Care
Room 313
Hayfield House
Hayfield Road
KIRKCALDY
Fife KY2 5AH
Tel 01592 643355
www.show.scot.nhs.uk/fpct

Date 6 September 2010
Our Ref 10-051 10/S1401/31
NRS10/MH31
Enquiries to Aileen Yell
Tel No 01383 565110
Email aileen.yell@nhs.net

Dear Miss Davis

Project Title: Moving on? People with learning disability and forensic history : views on receiving high levels of staff support as a form of rehabilitation in the community

Thank you for your application to carry out the above project. Your project documentation (detailed below) has been reviewed for resource and financial implications for NHS Fife and I am happy to inform you that Management Approval has been granted.

Approved documents

Document	Version	Date
Protocol	1	4 May 2010
Investigator CV		12 August 2010
REC application		4 May 2010
Participant Information Sheet	5	9 July 2010
Participant Consent Form	5	2 August 2010
References	1	4 May 2010
Relevant Safety Protocols for client interview	2	27 May 2010
Interview Guide (for researcher)	2	20 May 2010
Evidence of insurance or indemnity		13 July 2010
REC letter giving conditional favourable opinion		1 July 2010
REC letter confirming evidence of compliance with approval conditions detailed in their letter of 01.07.10		4 August 2010
Amended REC letter		24 August 2010
NRS-CC Certificate of Compliance		31 August 2010

I note that the favourable ethical opinion applies to all NHS sites taking part in the study therefore no separate Site Specific Review is required in this case.

The sponsors for this study are the University of Edinburgh.

Details of our participation in studies will be included in annual returns we are expected to complete as part of our agreement with the Chief Scientist Office. Regular reports of the study require to be submitted. Your first report should be submitted to Dr A Wood, R&D Manager, R&D Resource Centre, Lynebank Hospital, Halbeath Rd, Dunfermline, KY11 4UW (Amanda.wood3@nhs.net) in 12 months time and subsequently at yearly intervals until the work is completed.

In addition, approval is granted subject to the following conditions:-



6.6 Appendix 6 – Letter to care provider managers

Psychology Department
Lynebank Hospital
Halbeath Road
Dunfermline
Fife KY11 4UW
Telephone 01383 565210
Fax 01383 565409

Private & Confidential

Date 3/9/10
Your Ref
Our Ref AD

Enquiries to AD
Extension 5210
Direct Line 01383 565210

Dear Team Manager

Re: Research study - Moving on? People with learning disability and forensic history: views on receiving high levels of staff support as a form rehabilitation in the community

My name is Alana Davis, I am a Specialist Psychological Practitioner working within NHS Fife. I am also working towards a doctoral qualification with the University of Edinburgh. As part of the fulfilment of my doctoral thesis I will be carrying out research over the course of the next year. The project has been reviewed and approved by the East of Scotland Research Ethics Service, and by the Research & Development department at NHS Fife.

The potential participants for the study are people with learning disability and forensic needs living in the community, who are supported by agencies like your own. I hope to conduct interviews, with those service users who consent to take part, looking at client views of rehabilitation in the community. There has been very little work done in this area, despite the importance of considering the views of these individuals in shaping future services.

Initially, I will be contacting service users, via members of their clinical team, to ask if they would be prepared to meet with me to discuss the study. If they agree to this, I would really appreciate if you could help clients, where appropriate, to go through the study information in order to make their decision about whether to take part in the study.

For those service users who choose to participate, the study involves two separate visits to their home. The first visit will be to shadow them for a half-day in order to get to know the individual and find out more about their day-to-day routine. The second visit will be to conduct a confidential interview with them. If a client supported by you chooses to take part, I will be in touch to ensure that a member of staff will be supporting the individual during my visits.

The information I collect will be confidential, and will be anonymised excluding all identifiable information. The results from this research will be summarised and written up, however, following completion of the study next year. This data will be made available to relevant parties, including care providers and other professionals.

Although it is beyond the scope of the current study, I hope that at some point in the future there will be an opportunity to interview forensic care staff about their views on community rehabilitation.

If you want to ask me any questions I can be contacted by phone (01383 565210) or email (alanadavis@nhs.net).

Thank you for your time.

Yours faithfully,

Alana Davis
Specialist Psychological Practitioner

6.7 Appendix 7 – Risk related protocols for use during interview

Moving on: Community rehabilitation for PWLD and a forensic history

Relevant safety protocols for client interview Version 1

16/5/2010

1) General risk procedures to be followed for the 1:1 participant interview:

Consistent with the lone-worker departmental policy:

- The researcher will make either the departmental secretary, or a colleague in the department aware of:
 - the address they are planning to visit
 - how long they intend to be
 - a mobile number on which they can be contacted
 - the client's home phone number/staff mobile
- The researcher will agree to call the secretary/colleague immediately following the visit
- If the researcher has not been in contact 15 minutes after the agreed time the secretary/colleague will attempt to phone the researcher's mobile number
- If there is no answer, they will telephone the client's home number, and will ask for the researcher
- If no answer is received they will again attempt to call the researcher's mobile phone
- If no answer is received they telephone the police advising them of the situation

During the interview:

- The researcher will carry a personal alarm during all 1:1 participant interviews – when the top half of the alarm is separated from the bottom the alarm a loud piercing sound emanates from the device
- Before the beginning of the interview the researcher will meet with both the staff member and the client and agree the following:
 - If the researcher feels in any way threatened during the interview they will activate the personal alarm
 - The staff member will stay within a reasonable distance to the room in which the interview is taking place so that they would be able to hear the personal alarm, should it need to be sounded

- If the staff member hears the alarm sounding they will come to the assistance of the researcher, entering the room to check that everything is ok
- After checking that the alarm has not gone off in error, and there is indeed a dangerous or threatening situation, the staff member will set in motion their emergency risk management procedures

2) Disclosures during interview

- Prior to the beginning of the interview the researcher will advise the client of the following:

'If, during the interview, you tell me something about you causing harm to others (which I don't know already), or about someone harming you (which I don't already know about), I would need to pass that on to someone else.'

- If a disclosure occurs during the interview (about either harm the participant has caused, or plans to cause to cause, or about harm that has been caused to them), the following will happen:
 - The interview will be temporarily stopped
 - The researcher will explain that the participant had told them information which they would need to pass on to someone else, as discussed at the beginning of the interview
 - The participant will then be asked if they wish to continue with the interview
 - If they do not the interview will be terminated and the participant can make a decision about whether they would want to carry on with the interview at a different time, or not at all
 - The information obtained will be passed onto the clinical supervisor, and to relevant parties thereafter (depending on the nature of the disclosure)

6.8 Appendix 8 – Distress related protocols for use during interview

Moving on: Community rehabilitation for PWLD and a forensic history

Relevant safety protocols for client interview Version 1

16/5/2010

In the case of distress during interview the following protocol will be implemented:

- If the participant becomes angry or distressed during the interview they will be asked if they would like a break or wish the interview to be terminated. If they indicate the latter the researcher will stop the recording and terminate the interview.
- The researcher will ask the participant if they would like their staff member to come into the room or if they wish the staff member to contact someone else on their behalf. The researcher will also offer helpline numbers (Breathing Space, Samaritans) in the case that the participant does not wish to speak to anyone else.
- The researcher will ask if the participant wishes to leave, or wishes them to leave (depending on the interview venue). If the participant answers in the affirmative the researcher will leave/the participant will leave but the researcher will ensure that a member of staff is present when this happens.
- Staff and client will be reminded that information regarding placing a formal complaint about how the research has been conducted is available in the Participant Information Sheet