An Exploration of the Relationship Experiences of Men with an Intellectual Disability in Secure Settings.

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Declaration

I declare that the work contained within this thesis has not been submitted for any other degree, or to any other institution.

Abstract

This thesis adds to the literature on offenders with intellectual disabilities (ID). The literature review synthesises studies which assessed the prevalence and impact of comorbid personality disorder (PD) and ID in forensic samples. It is concluded that existing literature is valuable but limited since the current conceptualisation and assessment of PD in ID populations is weak. More stringent methods of diagnosis are required to investigate this further.

The research report explores the relationship experiences of men with ID who are detained in secure services under the Mental Health Act. Qualitative methodology was utilised in order to give participants a research voice, and interview transcripts were analysed using Thematic Analysis (TA). The analysis yielded three superordinate themes; 'interpersonal factors', 'the internal-external interface' and 'safety'. These findings are discussed in terms of the impact positive and negative relationship experiences have upon sense of self, behaviour and the attribution of responsibility. The journey through the forensic system and the consequences of being detained are also discussed. The findings are highly relevant for clinicians working with people with ID in forensic services. Further research is required to make sense of these results in non-ID populations.

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Personality Disorder, Intellectual Disability and Offending Behaviour

Abstract

This review critically appraises studies where personality disorder (PD) has been explored as a descriptive or possible predictive factor in offending behaviour in individuals with an intellectual disability (ID). Thirteen studies were included in the review. Methodological limitations and problems in accurate diagnosis of PD within this client group preclude firm conclusions being reached. These limitations are discussed along with synthesising the findings of the studies in relation to prevalence and association with ID and offending. It is concluded that further research should be conducted, with particular attention paid to the conceptualisation and assessment of PD.

1 Introduction

1.1 The Significance of PD

In recent years, there has been a growth in the research and clinical interest in Personality Disorder (PD). The construct of PD, from assessment to treatment, its association with offending behaviour and deliberate self-harm in the general population (Brown et al., 2002) and its conceptualisation has not been without controversy (Saulsman & Page, 2004). Some practitioners even question its existence. The bulk of the literature on PD to date has concerned people who access mainstream mental health and forensic services. The issue of comorbidity of intellectual disability (ID) is starting to attract research interest, and there is now an emerging literature on PD in forensic ID populations. The purpose of the current review is to systematically evaluate the emerging literature.

Concurrent to this emerging literature, changes in the political context of PD have been reflected in changes to UK government policy and law. "Managing Dangerous People with Severe Personality Disorder" (1999) was published as a joint venture between the Home Office and the Department of Health. It sets out new proposals to protect the people who have dangerous and severe PD (DSPD) and the general public. The document outlines changes to criminal and mental health law, enabling people with DSPD to be detained indefinitely in prison or secure hospitals for as long as they present a danger.

These changes to the law were reflected in subsequent policy guidance "Personality Disorder: No Longer a Diagnosis of Exclusion" (2003). The

guidance stated that although the previous mental health legislation specified that a condition must be “treatable” to warrant detention (i.e. treatment must be likely to alleviate or prevent deterioration), this was not the case in the newer legislation. In response to many clinicians believing PD is not a treatable mental disorder, The Mental Health Act (2007), removed the treatability clause and provided a generic description of “mental disorder”.

1.1.1 The Impact of PD

PD is described by the American Psychiatric Association as “an enduring pattern of inner experience and behavior that deviates markedly from the expectations of the culture of the individual who exhibits it” (APA, 2000, p686). These inner experiences and patterns of behaviour can lead to difficulties in living with oneself and other people. These “failures to achieve adaptive solutions to life tasks” (Livesley, 2001, p13) can include problems in relationships and relating to others, struggles with emotion control and regulation and offending behaviour.

PDs are distinguished from mental illness by their enduring nature and the hypothesis that they are due to extreme variations of development rather than pathological processes (Kendell, 2002). Although separate entities, PDs are often comorbid with mental illness (Casey, 2000), which can be problematic; PD can affect patients’ ability to form useful relationships with therapists, potentially reducing the effectiveness of psychological and social interventions for mental health problems (Kendell, 2002).

Epidemiological surveys have shown that antisocial PD (ASPD) is a common disorder, with a prevalence rate of 2-3% among community samples. This figure rises to 60% among male prisoners (Moran, 1999) and is the prominent subtype in inpatient and outpatient forensic services (Rotter et al., 2002). In a systematic review of studies involving almost 23,000 male and female offenders, 42% had a diagnosis of PD (Fazel & Danesh, 2002). Over a fifth of this sample had ASPD, which indicates prisoners are approximately ten times more likely to have this diagnosis than the general population.

There are well-established links between borderline PD (BPD) and self-harm, a diagnostic criterion in DSM-IV (2000). Comorbidity of BPD with a major depressive episode increases the number and seriousness of suicide attempts (Soloff et al., 2000). Non-suicidal self-harm is often intended to express anger, punish oneself, or regain "normal" feelings through distraction, while suicide attempts are attributed to an effort to improve the lives of others (Brown et al., 2002).

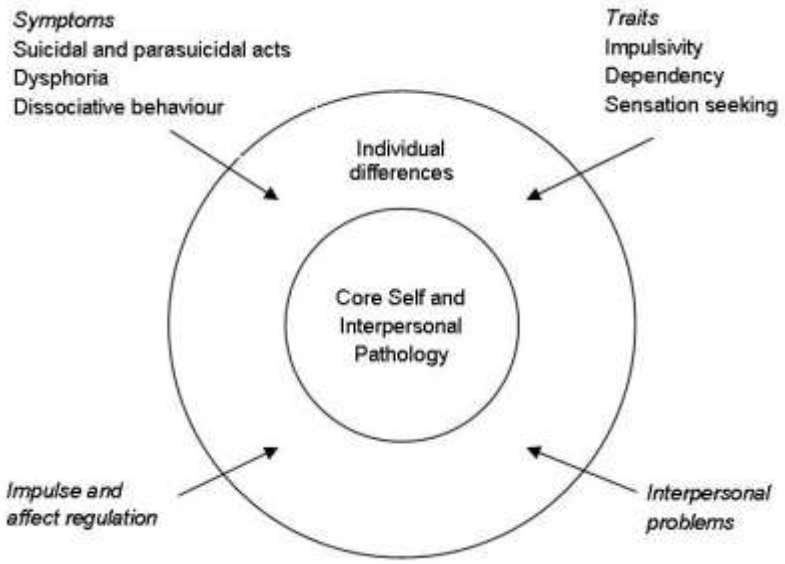
1.1.2 The Origins of PD

Knowledge about the origins of PD has increased in recent years, however there are still significant gaps in understanding (Kendell, 2002). It is acknowledged that PDs have observable origins in the early years of life (De Clercq & De Fruyt, 2007) and the available evidence indicates that PD arises from a "complex array of psychosocial and biological factors" (Livesley, 2003, p56). Conduct problems have been shown to be predictive of ASPD independently of associated adverse social and family factors (Hill, 2003).

PDs in adulthood can be traced back to adolescent emotional and disruptive behaviour disorders (Helgeland et al., 2005), with childhood hyperactivity considered a crucial factor in the development of psychopathic tendencies in later life (Friedenfelt & af Klinteberg, 2008). Emerging severe PD traits have been associated with higher levels of psychosocial adversity, antisocial behaviour, convictions and sexually abusive behaviour in adolescence (Vizard et al., 2007).

It is clear that there is no evidence for one primary risk factor of PD. Livesley (2003) presents a model of PD (see Figure 1) based on the theory that these common factors of bio-psychosocial adversity are core aspects, with attention paid to the impact of individual differences. He uses this model to inform treatment, suggesting interventions need to address core self and interpersonal pathology, along with targeted specific interventions to treat idiosyncratic characteristics.

Figure 1: The Structure of PD (Livesley, 2003)



1.1.3 Comorbidity of PD and ID

Diagnosing PD in people with ID is a contentious issue (Naik et al., 2002). Some authors suggest that the high rates of comorbidity raise questions about the validity and reliability of seeking to assess people with ID for PD and the clinical value of this (see Alexander & Cooray, 2003 below). It appears that the majority of PD diagnoses in ID are restricted to mild or borderline ID, as many of the diagnostic criteria rely on cognitive and verbal abilities (Naik et al., 2002).

Diagnostic overshadowing continues to exist, with clinicians more likely to recognise a wide range of psychiatric symptoms in those with IQs in the normal range than in those with ID (Mason & Scior, 2004). It has been suggested that BPD and dependent PD (DPD) are sometimes incorrectly diagnosed in people with ID, with the diagnosis reflecting the necessary dependence that some people with ID have on their caregivers (Pridding & Procter, 2008).

1.2 Aims

This review aims to draw together the literature on PD in offenders with ID. Insights into the prevalence, assessment and longer term outcomes within this specialist client group will be discussed, with an emphasis on the methodological and conceptual challenges that currently exist.

2 Search Strategy

2.1 Databases and Search Terms

A search of PsychINFO was conducted for papers on “mental retardation” OR “learning disability”, “personality disorder” and “offending”. These search terms were mapped, for example, searching for “mental retardation” automatically searched for “intellectual disability” and “developmental disability”. The search was limited to peer-reviewed articles written in the English language. This search yielded 25 papers, by checking the reference section one further relevant paper was identified. The PsycINFO search was then repeated using MEDLINE, Social Science Citation Index (Web of Knowledge) and PsycArticles and an additional eight, one and five papers were found respectively. The reference sections of these papers produced no more. 40 relevant papers were identified in total.

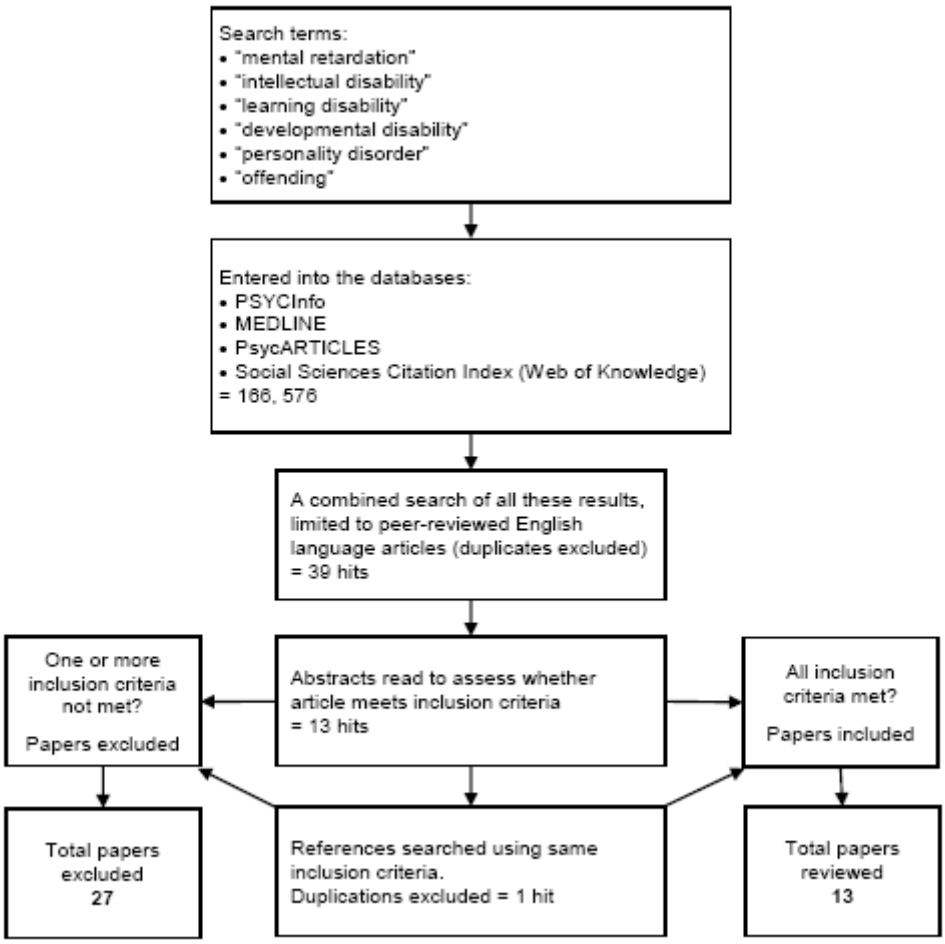
2.2 Inclusion criteria

The 40 relevant papers were read in full. Any papers that did not explicitly measure PD were excluded, as were those that did not sample from an ID offender population. The reference sections of included papers were searched for titles containing "personality disorder", "intellectual disability" (or former equivalent terminology) and a mention of forensic sampling or offending behaviour. Studies aiming to assess the validity and reliability of the Psychopathy Checklist-Revised (PCL-R; Hare, 1991) are excluded since the critical evaluation of these endeavours is beyond the scope of the present review.

2.3 Search Results

In total 13 papers were identified as falling within the inclusion criteria (see Figure 2 below). Table 1 contains full details on the studies included and is located at the very end of the review.

Figure 2: Literature Review Search and Inclusion Process.



Three review papers were found during the search. O'Brien (2002) reviewed comorbid ID and psychiatric disorder excluding PD in offenders, and Alexander and Cooray (2003) examined literature on ID and PD in the non-forensic population. The former was found in the original database search, with the latter found in the search of the reference lists. In addition, Torr (2008)

reviewed comorbid ID and PD in offenders. This review is not currently listed on any of the searched databases and was not cited in any reference lists. This paper was located through an internet search engine.

2.4 Data Collection and Analysis

To fulfil the review aims, data extraction included

- aims and design of the study
- participants and setting
- assessment methods and measures
- findings
- limitations and
- conclusions and implications.

As the review involved studies with diverse methodologies and aims, a hierarchical rating system was not used to assess quality of research evidence.

3 Previous Reviews

There has been one published review to date examining PD in forensic ID samples (Torr, 2008). This was a brief, selective review; the author identifies it as “illustrative rather than exhaustive” (p4). Although search terms were defined, no inclusion criteria were offered. There is no clear sense of the number of studies that were critically evaluated. The present systematic review contains 13 papers, six of which overlap with Torr (2008), and three of which have been published since that search was conducted. There are two studies within the present review that span the dates included in Torr’s review, but were excluded without explanation.

Torr (2008) points out that the problems of diagnosing PD are complicated by confounding factors in ID such as developmental abnormalities that affect cognition, emotion regulation and dependency on others that are secondary to adaptive skills deficits. She does state that there is increasing rigour in diagnosis, although the studies she cites to support this awarded diagnoses on information gathered for the purposes of research. There is no critique of the quality of diagnoses using clinical file information.

There is a brief discussion of studies that assessed the validity and reliability of the PCL-R and assessments of anger in Torr (2008), however the critique of these is limited to re-iterating the problems of using assessments within a client group for which they have not been fully normed. In response to criticisms of studies not differentiating between offenders with ID and those with borderline intelligence, the primary recommendation is that these groups should be

compared in future research to explore whether rates of PD in ID offenders are artificially inflated by including people of higher intelligence in studies.

Alexander and Cooray (2003) examined published literature on the diagnosis of PD within ID samples. Their main finding was the variation in the prevalence of PD; 1-91% in the community and 22-92% in hospital samples. The authors assert that discrepancies so large cannot be explained by genuine differences in the sample, and thus reflect problems in the conceptualisation and assessment of PD within this client group. For example, these problems include potentially irrelevant mainstream diagnostic criteria being imposed onto a group who have reduced cognitive ability, diagnostic overlap and overshadowing. In addition, many of the studies included in the review were designed to look not specifically at PD, but at all psychiatric problems in ID. Alexander and Cooray (2003) recommend future research should be directed towards developing a consensus of diagnostic criteria and assessments for each PD specific to the ID client group.

O'Brien (2002) reviewed prevalence of mental health problems in people with ID, along with the most established measurement tools for dual diagnosis in ID. He excluded literature on PD without explanation. O'Brien found that although there is a substantial literature on dual diagnosis in the mainstream ID population, the same is not true for forensic ID samples. He notes that while there has been a growing interest in offenders with Autistic Spectrum Disorder (ASD), the majority of the available evidence comes from case studies. O'Brien suggests that focusing on dual diagnosis in forensic ID samples is not a priority

due to a perceived overlap between clinical inpatient and detained forensic samples. O'Brien (2002) goes on to say that "treatment research is not ideally pursued in offender populations" (p27). However, while it may be the case that confounding variables make research in secure hospitals challenging, it would be unwise to assume that what is effective, relevant or important for staff and service users accessing mainstream clinical services would be equally effective for those who had committed offences and are detained within secure settings.

4 Empirical Studies Focusing upon PD, ID and Offending

The articles contained in this review comprise six prevalence studies, two outcome studies and five association studies. Of these association studies, two examined the ability of childhood neuropsychiatric symptoms (including ID) to predict adult psychopathy and three explored PD as a predictor of future rule-breaking following discharge from services.

Five of the studies were retrospective file review studies based on historical information recorded for clinical reasons. The remainder used collateral information alongside interviews and assessments with participants or informants and direct observations from nursing staff. The majority (6/7) of the association and longer-term outcome studies used file information for pre-discharge information and informant assessments for post-discharge comparisons.

4.1 Prevalence

Five of the six prevalence studies sampled from forensic ID populations across the spectrum of security from community services to high secure hospitals. The remaining study (Lunsky et al., 2009) studied 1,971 male and female adults with (369) and without (1,602) ID who were in receipt of inpatient services. Lunsky et al. (2009) aimed to examine gender differences in psychiatric diagnoses in adults with and without ID using the Colorado Client Assessment Record, an assessment tool that explored patient functioning along with DSM-IV mental health diagnosis and the presence or absence of ID. The assessment information was gathered from staff including those who knew the participants

well. It was discovered that women were 1.08 times more likely than men to receive a diagnosis of PD if they had ID and 1.29 times more likely if they did not have ID. Mood disorders were more than twice as common in women, both with and without ID. This overall pattern of gender differences is similar for those with and without ID, suggesting that gender is a relevant variable to consider when caring for psychiatric inpatients with and without ID.

The bulk of the remaining studies were retrospective and based on file information. One (Lindsay et al., 2006) utilised further data from interviews with clinicians, the completion of the Standard Assessment of Personality (SAP; Pilgrim & Mann, 1990) and direct observations of participants. Lindsay et al. (2006) studied 164 men from three forensic ID services, with a comparison of the prevalence of PD between forensic community, medium/low secure and high secure settings. Service users from medium and low secure units were grouped together although the services described differed. Likewise, the community group included people who resided on a 10-bed open ward as well as those living in community placements. No rationale was given for these groupings. Attempts were also made to assess the predictive validity of the PCL-R however, given the scope of this review attention is not paid to this aspect of the study.

Of the whole sample, 39.3% were considered to satisfy fully the diagnostic criteria for at least one PD. In the high secure setting, 52% had at least one PD compared to 26.2% and 33.3% of those detained in medium/low secure conditions and those in the community respectively. The most common PD was

antisocial (ASPD, 36%). A significantly larger number of ASPD diagnoses were made within high secure and forensic community settings. Rates of diagnosis of ASPD were 38.5% in the high secure sample, with a rate of 22.1% in the whole sample. Surprisingly the rate of ASPD seen in the community setting was higher than that seen on the medium/low secure setting.

Lindsay et al. (2007) made DSM-IV diagnoses of PD on the same 164 patients as Lindsay et al. (2006). They ascertained that despite the relatively high occurrence, the total prevalence is lower than some estimates for non-forensic community samples of people with ID. The authors attribute this to the care they took to make the diagnoses and the use of several information sources.

Mannysalo et al. (2009) conducted a register-based prevalence study of PD in 44 people in Finland who had ID and a forensic history. They found that over a third of the sample had ASPD or BPD, and that PD was the highest co-morbid mental health problem after substance misuse. A third of the sample had a "triple diagnosis" of ID, mental illness (including PD) and substance misuse. Like Lunsky et al. (2009), they also found that more women than men were diagnosed with PD. Their findings are comparable with prevalence rates of among the ID population with regard to offence type, substance abuse and most mental illnesses (including PD) identified in previous studies.

Devapriam et al. (2007) conducted a retrospective file review of all 1100 forensic ID patients who had contact with the local ID psychiatric services within the last 20 years. They found that 15 (1.36%) had committed arson; these 15

comprised the study sample. Mental illness was noted in one patient as the direct cause of the offence (command hallucinations in psychosis), with 60% of the sample having a psychiatric diagnosis. All had been in contact with psychiatric services prior to the offence and 80% had PD (borderline or antisocial). The most common reason for fire setting within this group appears to be revenge, followed by suggestibility.

Hogue et al. (2006) conducted a retrospective file based prevalence and comparison study. Information was taken from clinical records, and in the instances where there was uncertainty regarding reliability or integrity of information further details were taken from nursing or support staff. The sample comprised 73 high secure, 70 medium/low secure and 69 community offenders with ID. Hogue et al. (2006) found the more complex presentations, in particular PD, were found in the high secure group, with 54% of high, 10% of medium/low and 1.4% of community patients receiving a diagnosis of at least one PD. Three variables contributed to the ability of the regression model to predict level of security; having a lifetime conviction for murder, having caused criminal damage and having an ICD-10 (WHO, 2001) classification of PD.

4.2 Long-term Outcomes

There are just two published studies that looked solely at longer-term outcomes exploring the constructs of ID, PD and offending behaviour. Alexander et al. (2006) conducted a long-term outcome study of patients discharged from a medium secure unit for people with ID. They sampled over two time periods; cohort one 1987-1993 (n=27) and cohort two 1994-2000 (n=37). Of cohort one,

a third had a diagnosis of PD; 22% had dissociative PD (DiPD) and 11% had other PDs. In cohort two, 21% had a PD diagnosis; 13% had DiPD and 8% had other PDs. Case notes were reviewed and an interview was conducted with key informants to elicit information on re-conviction, offending-like behaviour, relapse and re-admission. The main associations of reconviction were with a previous offence of theft or burglary, the presence of PD, and age of less than 27 years.

Kunz et al. (2004) conducted a three-year follow up study of 85 patients after leaving an inpatient treatment programme for mental illness and repeated aggression, or crime, or both. The study sample represents approximately 50% of those who started the programme. On the basis of follow-up data, patients were classified into three mutually exclusive groups; stable (n=33), re-hospitalised (n=35), and re-arrested (including those who were hospitalised and arrested at different times; n=17). Almost half of the sample had PD, and 28% had ID. Frequent violent offences prior to treatment were seen in those with higher re-arrest rates, alongside significantly higher PCL-R scores, substance abuse and treatment non-compliance. IQ did not differentiate the three groups. The authors attributed this to patients with higher IQs completing the original treatment programme and those with lower IQs terminating treatment before the end.

4.3 Associations of PD with Offending/Childhood Neuropsychiatric Problems

Five association studies have been included in this review. Three examined PD and offending, and two explored childhood predictors of PD in adulthood. Chan

et al. (2003) conducted a file review to examine the association between ID, psychiatric disorder, and offending behaviour. They hypothesised that if people with ID and mental health problems are more likely to commit offences then there would be a high percentage of comorbidity among the referrals. Of 276 individuals referred to the Mental Health Review Tribunal, 17 (6.15%) had ID and psychiatric disorder of which three had a diagnosis of PD (17.6%). This represents an inflated incidence of ID, and psychiatric disorder was seen in more than half the sample.

Crossland et al. (2005) examined 60 people detained in high or medium secure settings who had ID. They compared ID only (n=12), ID+PD (n=22) and ID+mental illness (n=16) using case history, a mental state examination and a review of collateral information. The remaining ten formed subgroups that were too small for statistical analysis. Similarly to Lindsay et al. (2006) a diagnosis of PD was associated with placement in a high secure setting. Individuals with a diagnosis of ID only were most likely to be detained in specialist ID/mental health services outside their geographical area of origin. Those individuals diagnosed with ID and PD had higher average IQs, while those with ID alone had the lowest. There were differences in the length of stay of the three groups, with ID+mental illness having the best prognosis, followed by ID+PD then ID alone.

Lidher et al. (2005) aimed to describe the findings of a 5-year follow-up of a community sample (n=75) of people with ID and to explore any association between the presence of PD and behavioural problems, psychiatric disorders

and use of specialist services or psychotropic medication. Information was gathered through the use of interviews and assessments with family or staff members who had known the participant for at least five years. Of the sample, 28% had ID and PD; the remainder did not have PD and were considered the control group.

It was found that more people who had a diagnosis of PD had a psychiatric diagnosis, were prescribed medication and used specialist services when compared to controls. This supports the findings by Mannysalo et al. (2009) that a high proportion of ID offenders have a "triple diagnosis". A significantly higher proportion of individuals with PD had a history of offending behaviour compared with the control group.

Söderström et al. (2004) examined 100 perpetrators of violent crimes referred for forensic psychiatric court assessments. They aimed to ascertain the association between childhood neuropsychiatric disorder and adult violence. They found that the prevalence of childhood-onset neuropsychiatric disorders was considerably higher among the participants in this study than in the general population. A few strongly interlinked conditions, including ADHD and conduct disorder, substance abuse and high PCL-R scores were more closely associated with violent behaviour than all other psychiatric ratings, despite the high rates of mental illness in the study population. The PCL-R scores – particularly for the behavioural factor – were superior to all DSM-IV definitions of PD in identifying traits linked to violence. Anckarsäter (2005) studied 89 of the same participants and found that neuropsychiatric symptoms and personality

pathology such as psychopathy share common symptoms. Executive deficits and social interaction problems were noted in half the sample; most frequent were disruptive behaviour disorders such as ADHD and conduct disorder. The proportion of participants with ID was also substantial.

4.5 Evaluation

4.5.1 Sampling

The vast majority of the studies included in this review had small participant numbers (Kunz et al.; 2004, Lidher et al., 2005; Alexander et al., 2006; Devapriam et al., 2007; Mannysalo et al., 2009). This reduced the power of and options for statistical analysis, and ultimately the confidence one can place in the findings. Lunsky et al. (2009) note that that their small sample size ruled out the possibility of analysis on the basis of demographic details. In the one study that had a larger sample size (Hogue et al., 2006), a considerable number of statistical comparisons were made. In spite of the authors setting alpha levels at a more conservative .001, in conducting multiple comparisons there is a greater probability of a type I error.

Many of the authors acknowledged a sample bias, both through necessity of gaining access to the desired numbers of participants (Hogue et al., 2006) and through the commission of specific offences or institutional incidents (Devapriam, et al., 2007; Lindsay et al., 2006). There is also recognition in many of the studies that given the settings in which the bulk of this research was conducted, samples are often highly selected by virtue of their forensic and mental health histories, and the environments in which they reside (Lindsay, et al.; 2007 Alexander et al., 2006). Many study samples comprised “an extreme

subgroup with severe offending" (Mannysalo et al., 2009, p286), or individuals who had mental heath needs that were being served by tertiary level psychiatric hospitals (Lunsky et al., 2009). The vast majority of the participants were male (e.g. Crossland et al., 2005), with most studies including only male participants (Lindsay, et al., 2007). Most often, this was due to data collection taking place in male-only settings.

Aside from the inherent selection biases, Lidher et al. (2005) employed inclusion criteria that only those individuals who had PD could be included in their final analysis excluding individuals with abnormal personality traits. In any case, Hogue et al. (2006) point out that while no sample biases such as inclusion/exclusion criteria were used in the selection of participants for their study, it is possible that there were selection biases in the way patients were selected for services. This could be true for all participants in all studies conducted in forensic or mental health settings.

There was a degree of overlap in the groups of Hogue, et al. (2006) where some participants had been stepped down from high secure services to medium, and their information may have been included in both groups at the time of the analysis. Security categories were also arbitrarily grouped together, such as and low and medium secure (Hogue et al., 2006). The same sample was used in two association studies (Anckarsäter, 2005; Söderström et al. 2004). Although the aims and findings were slightly different there is a danger once more that the studies were not independent, and therefore the papers will support the findings of the other. This is also true for some of the papers written

by Lindsay and his collaborators. Finally, there were problems of attrition, and within that a recognition that those who completed a treatment programme had better cognitive abilities (Kunz, et al., 2004).

The consequence of these sampling constraints is the lack of confidence one can have in the generalising of these results to other sub-samples of people with ID, such as those in the forensic community population or those who have not committed offences (Chan et al., 2003; Kunz, et al., 2004). As Crossland et al. (2005) point out, the forensic ID population is a heterogeneous group with wide-ranging needs; the value of these studies using specific samples is of immense clinical and research value for enhancing understanding and care of particular groups.

4.5.2 Assessments and Diagnostics

A theme throughout the research in this field is the lack of accurate diagnosis of both ID and PD. Chan et al. (2003) note that the prevalence rates in their studies may be underestimated as there is a lack of formal assessment for ID when individuals with psychiatric disorders enter police custody. Furthermore, there are difficulties in research measurement due to changing terminology of ID and offending behaviour, changes in the criminal justice systems and issues with reporting and classifying offences (Devapriam et al., 2007).

Many of the studies included in this review relied on file information. Occasionally, demographic details were missing (Chan et al., 2003), and there was an appreciation that the studies will only be as good as the quality of the clinical notes and reports on file (Hogue et al.; 2006, Alexander et al., 2006). In

some cases notes had insufficient detail, so judgements could not be made on constructs such as seriousness and frequency of some offence behaviours (Hogue et al., 2006), and in some instances not all participants could be rated on all variables (Kunz et al., 2004). Furthermore, information on level of disability and demographic information was sometimes unavailable, and the accuracy of diagnosis of ID and psychiatric disorders could not be verified (Lunsky et al., 2009).

Some studies diagnosed PD from clinical records with information triangulated from four sources, with diagnosis criteria being agreement on three. The inter-rater percentage agreement regarding the most commonly diagnosed PD (ASPD) was 72.6%, the lowest agreement for any category (Lindsay, et al., 2006). In a further study by the same authors, inter-rater agreement on all PD was 78.7%, which was technically classed as an outlier (Hogue et al., 2006). These levels of agreement reduce the confidence one can have in such findings.

Lidher et al. (2005) used informant-report measures to diagnose ID and mental health problems. The measures used have been shown to be valid and reliable within the population studied, and informants may experience less social desirability bias in their answering. However, informant-report measures depend on the informant knowing the person being assessed well, and not allowing their own positive or negative relationship experiences with that person to affect their responses. Furthermore, the measure of psychiatric symptomatology only covered the previous four weeks. The studies examined

here relied often solely, or in part, on historical information that has not been recorded with research needs in mind. This is particularly problematic when consideration is given to the association and outcome studies, where historical clinical information was compared with current informant-based assessment results designed for academic purposes.

Söderström et al. (2004) indicate that in their study childhood diagnoses were not given as readily in the older participants. In retrospective diagnosis there may have been problems in accurate recall or biases towards attributing problems to diagnosable conditions to free participants or their environments from blame. However, it is also pointed out that, although retrospective diagnoses of childhood problems in adulthood are fallible, they are necessary in clinical research as it is impossible to assemble prospective population-based cohorts of specific disorders, particularly when trying to associate them with negative events such as offending (Anckarsäter, 2005).

Criticisms must be considered in the context of the lack of research evidence (Crossland et al., 2005; Lunsky et al., 2009). The evidence base has to begin somewhere, and information about prevalence, associations and longer-tem outcomes of people with ID and PD is vital in order to understand how relevant this issue is. Finally, studies made stringent attempts to increase the reliability of findings. For example, Lindsay et al. (2007) took great care in the diagnosis of PD, which provides the reader with confidence in the findings.

4.5.3 Statistical Analysis

Hogue et al. (2006) conducted multiple statistical comparisons and, although alpha was reduced, there is still a possibility of reaching chance findings when a large number of tests are computed. Furthermore, Lunsky et al. (2009) applied no alpha corrections for the multiple statistical comparisons they conducted. The authors defend this decision as they did not want to be over-cautious and disregard potentially important findings when there is such a dearth of studies.

There were some problems with the inter-rater reliability of diagnoses applied using file information; Hogue et al. (2006) found inter-rater agreement on ASPD only 78.7%, which was classed as an outlier when viewed in the context of the agreements for other PDs. The same authors a year later (Lindsay et al., 2007) found inter-rater reliability for the classification of anti-social PD was lowest of all PD classification. Finally, Devapriam et al. (2007) conducted a prevalence study only with no statistical analyses. Söderström et al. (2004) scored PCL-R assessments on file information, where inter-rater reliability for behavioural and total scores was high, but for the affective scale was low.

5 Discussion and Conclusions

5.1 Summary of findings

This systematic review has critically evaluated 13 research papers concerned with the prevalence and impact of PD within ID forensic samples. These papers have found rates of PD in ID offenders between 1.4 and 54%. This wide range of rates reflects the problems discussed by Alexander and Cooray (2003), and suggests issues of conceptualisation and assessment of PD remain within this client group. Comorbid PD poses more problems than other mental illnesses post-discharge for offenders with ID, particularly when interacting with substance misuse, treatment non-compliance and young age. There is an association between ID and PD, and PD/high PCL-R score is a strong predictor of future violence. People with ID and PD are more likely to be prescribed medication and to have comorbid mental illness, and present more longer-term management problems to services.

5.2 Theoretical implications

Lindsay et al. (2007) point out that since the classification of PD is becoming increasingly incorporated into mental health legislation it is important that there is an understanding of the relationship between ID and PD. Crossland et al. (2005) found that IQ is a predictive factor in the PD group; the participants with PD and a higher IQ had a shorter average stay in secure hospital settings than the group that had ID alone and who had lower IQs.

Lindsay et al. (2007) found that correlations between the 10 PDs they examined

showed highly significant overlap. Interestingly, there was a medium effect size in the association between ASPD and BPD, the two most commonly diagnosed PDs in secure ID samples. This degree of overlap is concerning as it suggests that current diagnostic criteria are not sufficient to correctly identify personality pathology type. The same authors (Lindsay et al., 2006) have championed the use of multiple information sources before a diagnosis is given, which should be applied in clinical work as well as for academic purposes. As a result, in their study no diagnoses of dependent PD (DPD) were given. Over-representation of DPD in ID populations is commonly believed to be a result of misdiagnosis regarding the genuine and unavoidable dependence that people with ID have on services and family members. As PD diagnoses can be pejorative, particularly in conjunction with the already stigmatised ID diagnosis, they suggest that PD diagnoses should be reviewed annually in order to ensure integrity of classification and that diagnoses remain only if necessary.

5.3 Clinical Implications

Chan et al. (2003) feel the importance of identifying those at risk of offending cannot be overstated since failure to intervene at an early stage increases the risk of criminality. For the 17 cases they studied, mental health needs were unmet until a serious offence was committed. Interventions aimed at children with ID and their families, particularly those with conduct problems, seem most prudent in light of the findings that personality pathology shares symptoms and features with childhood onset neuropsychiatric problems (Söderström et al., 2004; Anckarsäter, 2005). ID offenders form a complex, poorly served and under-recognised group, and those exhibiting early warning signs should be

caught within support systems (Mannysalo et al., 2009).

Alexander et al. (2006) suggest that those with PD present the longer-term problems to ID services as the presence of a PD in people with ID significantly affects the patient's acceptance into community placements. Indeed, Hogue et al. (2006) found a prevalence of only 1.4% in community forensic samples, suggesting these patients are more likely to be detained in secure settings. Conversely, Lindsay et al. (2006) found a higher prevalence of PD in forensic community services than in medium and low security, suggesting that PDs can be appropriately managed within the community. Services within the community need to be briefed and equipped for the supervision and treatment of PD. There is a perceived 'dangerousness' attached to PD, and recent media coverage and the creation of specialist DSPD services may have contributed to this perception.

5.4 Limitations of the Review

This review is longer, more systematic and contains more papers than Torr (2008). It is also more transparent regarding the search and inclusion/exclusion process. In spite of this, there are some limitations. A lack of coherent constructs of PD and robust methods of diagnosis continue to prevent conclusive findings. Given the early stage of the evidence this is to be expected and must be accepted if the literature base in this area is to develop. Recent papers (Lindsay et al., 2006; Hogue et al., 2006; Lindsay et al., 2007) have attempted to be more rigorous in their application of diagnostic criteria and the

use of multiple information sources, and it is expected that these examples will be followed.

As article titles are brief, it is possible that relevant papers may have been missed from the second phase of the search process. Perhaps if all cited articles had been read then more papers would have been included. Although the small number of papers found may reflect gaps in the search process, it is more likely, given the recency of interest in PD in ID populations, that it reflects a genuine dearth of studies particularly as the articles included had a high degree of overlap in their reference lists.

5.5 Future Research

As authors of the included studies noted, there are few studies on ID and PD and as such findings should be considered as an invitation to replicate studies with larger or different samples. As some studies included have shown, women are more at risk of receiving a PD diagnosis. This effect was also found in non-forensic control groups. Given that the vast majority of the study samples comprised mainly or exclusively male participants, prevalence rates of comorbid ID and PD in people who do and do not commit offences may be higher than is currently thought. Research should pay attention to the experiences of women within the mental health and forensic systems, as this lack of knowledge may reflect unmet clinical needs.

PDs, particularly ASPD and BPD were more likely to be diagnosed in people detained in high secure services than in medium and low security, but not when compared to community forensic samples. This suggests that there are a number of people with ID and PD that are being successfully managed in community settings and it would be beneficial to have studies to examine this community forensic phenomenon. Qualitative approaches could be used to investigate the experiences of people currently accessing these services, to understand the relatively high rates of people with ID and PD living successful lives without detention. Such a broad investigation of the journey through the mental health and criminal justice systems, experiences of secure settings and the process of Axis I and II diagnoses would help drive changes to policy and clinical care.

Unlike Torr (2008), there is no examination of the validity of assessments of PD in this review. As Lindsay and Taylor (2005) conducted a review of the assessment of anger in people with ID, it would be prudent for a systematic review of the literature to be dedicated only to the reliability and validity of measures of personality pathology.

Table 1: Prevalence, Association and Outcome Studies of ID+PD.

Date and Author(s)	Sample Size	Assessments Used.	Key Findings and Implications	Limitations
Prevalence of PD+ID:				
Lunsky et al., 2009.	1, 971 inpatients with (396) and without (1,602) ID.	* Colorado Client Assessment Record.	* Women were 1.08 times more likely than men to receive a diagnosis of PD if they had ID, and 1.29 times more likely if they did not. * Mood disorders were more than twice as common in women, both with and without ID.	* No corrections applied for multiple statistical comparisons. * Information on level of disability, ethnicity and race is not available. Issues of accuracy of diagnosis of ID and psychiatric disorders cannot be verified. * Small sample size. * Sample represents an extreme subgroup.
Mannysalo et al., 2009.	45 cases of 44 offenders who had ID and had committed an offence.	* WAIS-R/WAIS.	* More than ⅓ of the sample have antisocial or borderline PD, the highest co-morbid mental health problem after substance misuse. * More women were diagnosed with PD than men. * A third of the sample had “triple diagnosis” of ID, mental illness (inc. PD) and substance abuse.	* Register based and retrospective study. * Sample represents an extreme subgroup. * Small sample size.
Devapriam et al., 2007.	15 (1.36% of 1100 forensic ID patients) who had committed arson.	* File information.	* Male fire setters were younger than female fire setters. * Mental illness was noted in only one patient as a direct cause (command hallucinations); however 80% had PD (borderline and antisocial). * 60% had a psychiatric diagnosis and all had been in contact with psychiatric services prior to the offence.	* Difficulties in measurement of ID and offending. * Small sample size. * No statistical analyses.
Lindsay et al., 2007.	164 participants with ID from three levels of security: 53 high, 42	* SAP. * DSM-IV PD	* The overall prevalence of PD in this sample was 39.3%. * ASPD was the most frequently recorded at 22.1%, followed by PNDOS at	* Inter-rater reliability for the classification of anti-social PD was low(est) – although still significant at the .001 level. * Sample comprised of male forensic patients and results might

	medium/low and 69 community.	criteria.	9.8%. * No significant relationships emerged between IQ and PD.	not be applicable to other populations with ID. * Although the sample size is larger than many reported in the literature, samples over 500 are needed for confirmatory factor analysis.
Hogue et al., 2006	73 high secure (L1), 70 medium/low secure (L2) and 69 community (L3) offenders with ID.		* More complex presentations, in particular PD were found in the high secure group. * Previous and current violent offence information was more frequently recorded for L1 participants, followed by L2 then L3. * Three variables: having a lifetime conviction for murder, having caused criminal damage and having an ICD-10 classification of PD contributed to the regression model.	* Inter-rater agreement on PD only 78.7% - classed as an outlier. * Although the sample size was 212 and alpha levels were set at .001, there were a large number of comparisons. * The sample was highly selected. * This study relies on case-note information, which therefore relies on the quality of that information. * Overlap between L1 and L2.
Lindsay et al., 2006.	164 (from a sample of 212) men from three forensic ID services.	* SAP.	* 64 (39.3%) were considered to satisfy fully the diagnostic criteria for at least one PD. * The most common PD was antisocial (36), followed by PDNOS (16). A significantly larger number of ASPD diagnoses were made within high secure and community settings. * ASPD in high secure sample was 38.5% and in the whole sample was 22.1%.	* Highly selected sample. * Inter-rater agreement regarding the most commonly diagnosed PD – ASPD – was 72.6%, the lowest agreement for any category.
Outcome Studies:				
Alexander et al., 2006.	Cohort 1 = 27 (1987-1993) and cohort 2 = 37 (1994-2000) patients discharged from a medium secure unit for people with	*File information. * CGI.	* The main associations of reconviction were with a previous offence of theft or burglary, the presence of PD and age less than 27 years.	* Small sample size. * The behavioural definitions and outcome measures were poorly defined and there was a reliance on file information. * The two cohorts were studied using slightly different methodologies.

	ID.			* Highly selected group.
Kunz et al., 2004.	85 patients, followed for three years after leaving an inpatient treatment program for mental illness and repeated aggression/crime/ both.	* WAIS-R or Beta-II. * PCL-R.	* 24 (28%) of the sample had ID, 40 (47%) had PD. Patients in the stable group had the lowest PCL-R scores. * A diagnosis of ASPD and a history of ID significantly differentiated the rearrested group from the other two groups. * Patients who were rearrested had significantly higher scores on PCL-R than the other two groups. * IQ did not significantly differentiate the three groups. * Substance abuse was significantly more prevalent in the rearrested group, who also had more non-compliance with medication.	* Small sample size. * The subsample of patients who completed the treatment program comprised patients with better cognitive abilities. * Lack of a control group who did not complete the program who were discharged.
Association Studies:				
Crossland et al., 2005.	60 people with ID detained in high/medium security.	* File information.	* A diagnosis of PD was associated with a placement in high secure setting or in the private sector. * Individuals with a diagnosis of ID were most likely to be detained in services provided by specialist ID/mental health trusts out of area. * There were minor differences in the length of stay of the three groups, with ID+MI having the best prognosis, followed by ID+PD then ID alone.	* Relatively small number of cases.
Lidher et al., 2005.	75 community participants with ID+PD.	* SAP. * DAS. * PAS-ADD.	* 21 people (28% n=75) had PD: five paranoid, one dependent, two dissocial, six impulsive, seven schizoid. * Those with ID+PD were more likely to have specialist input and have comorbid psychiatric problems.	* Reliance on informant-report measures. * PAS-ADD only covers last 4 weeks of psychiatric symptomatology. * Small sample size of people with PD.
Chan et al., 2003.	17 patients with ID who had been	* File information.	* 17 (6.15%) had ID and psychiatric disorder. 60% had mild-borderline ID.	* Highly selected sample. * Problems in assessment in custody; reliance on file

	referred to MHRT.		* Three people had a diagnosis of PD.	information.
Anckarsäter, 2005.	89 perpetrators of violent crimes referred for forensic psychiatric court assessment.	* SCID-I+II. * ASSQ. * ASDI. * PCL-R. * LHA.	* One or several childhood-onset neuropsychiatric disorders affected the majority of offenders. * Neuropsychiatric symptoms and personality pathology such as psychopathy share common symptoms. * 18 had ASD, global IQ<85 in 37, 17 of whom had IQ<70. 39 had ADHD, 24 had co-ordination disorder, and 48 had met the criteria for conduct disorder in childhood.	* Retrospective diagnoses given from file information. * Sample overlap with Söderström et al. 2004.
Söderström et al., 2004.	100 perpetrators of violent crimes referred for forensic psychiatric court assessment.	* SCID-I+II. * Y-BOCS. * ASSQ. * ASDI. * WAIS-R. * PCL-R. * LHA.	* The prevalence of childhood-onset neuropsychiatric disorders was considerably higher among the offenders than the general population. * The PCL-R – particularly the behavioural factor – was superior to all DSM-IV definitions of PD in identifying traits linked to violence.	* Retrospective diagnoses given from file information. * PCL-R scored on file information. Inter-rater reliability for behavioural and total scores were high, but for affective was low.

Assessment Details: ASDI (Asperger Syndrome Diagnostic Interview; Gillberg et al., 2001), ASSQ (Asperger's Syndrome Screening Questionnaire; Ehlers & Gillberg, 1993), Beta-II (Kellog & Morton, 1974), CGI (Clinical Global Improvement Scale, Guy, 1976), DAS (Disability Assessment Schedule; Holmes et al., 1982), DSM-IV PD diagnosis criteria (Diagnostic and Statistical Manual of Mental Disorders; APA, 2000), LHA (Life History of Aggression Scale; Coccaro et al., 1998), PAS-ADD (The Psychiatric Assessment Schedules for Adults with Developmental Disabilities; Moss et al., 1998), PCL-R (The Psychopathy Checklist-Revised; Hare, 1991) , SAP (Standardised Assessment of Personality; Mann et al., 1981), SCID I (Structured Clinical Interview for DSM-IV Axis I Disorders; First et al., 1996), SCID II (Structured Clinical Interview for DSM-IV Axis II Disorders; First et al., 1997), WAIS (Weschler Adult Intelligence Scale; Wechsler, 1955), WAIS-R (Wecshler Adult Intelligence Scale-Revised; Wechsler, 1981), Y-BOCS (Yale-Brown Obsessive Compulsive Scale, Goodman et al., 1989).

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Section 2: Research Report

A Qualitative Study to Explore Relationships of Men with an Intellectual Disability in Secure Settings.

Abstract

Background: Although relationships have been demonstrated to be a predictor of quality of life, with policies for people with intellectual disabilities (ID) being written to reflect this, there is a shortage of research into the relationships of people with ID who have broken the law. **Methodology:** The present study uses Thematic Analysis (TA) to explore the relationship experiences of 10 men with ID in secure settings. Attention is paid to past and current relationships, with the content and direction of interviews being guided by participants. **Results:** Three superordinate themes were discovered in the analysis. These were 'interpersonal factors', 'the internal-external interface' and 'safety'. **Conclusions:** Results provide support for the existing literature base on the importance of relationships and the impact that positive and negative relationship experiences can have on people with ID. Support is also found for theories of parentification in this client group, the externalising of responsibility and a lack of coherence in the individual narrative.

1 Introduction

1.1 Relationships in People with Intellectual Disabilities

In a study to obtain population norms on the relative importance of determinants of quality of life, respondents were most likely to endorse relationships with family or friends as the primary factor, even above their own health and finances (Bowler, 1995). The Department of Health/World Health Organisation (2001) has indicated that regular, meaningful contact with friends is an important factor for physical and psychological health and the White Paper "Valuing People" (DoH, 2001) considers facilitating meaningful friendships and relationships to be a primary objective of services working with and for people with intellectual disabilities (ID). The updated "Valuing People Now" (DoH 2009) recounts case examples of people whose lives have been enhanced through support in this area. There is also evidence to suggest that social interaction is correlated with physical health. Fujiura et al. (1997) found that Body Mass Index in people with Down's Syndrome was predicted by friendship and social opportunities even after diet and exercise were controlled for.

In spite of the accepted importance of relationships, Robertson, et al. (2001) studied the social networks of people with ID in residential settings and found that the median size of participants' social networks (excluding staff) was just 2 people. Furthermore, people with severe ID typically named service providers and staff members in their list of friends (Schalock & Genung, 1993).

Despite assertions that size of social network and number of friends is the critical protective factor in preventing loneliness (Duvdevaney, 2008), McVilly et

al. (2006) conducted a mixed-methods study and reached contradictory conclusions. They found that although there was a significant negative correlation between participant ratings of loneliness and the length of time they reported spending with their friends, there was no significant relationship between ratings of loneliness with the number of people nominated as part of the participants' social networks or the average frequency of contact with those network members. Analysis of qualitative aspects suggested that connection with and the value that was placed upon a social network were critical factors linked to loneliness: the absence of this connection appeared to contribute to their experience of loneliness.

Cummins and Lau (2003) suggest that despite belief, both in the research base and in practice, that people with ID's associations with non-disabled people are in some way superior, this is not the case. Knox and Hickson (2001) found in their small sample qualitative study that all the participants identified close relationships and all these relationships were with people who had ID. Within this sample, connections with non-disabled people were always more superficial and shorter-term. This was attributed by the authors to a sense of shared history. This preference for friendships with others with ID was replicated by Emerson and McVilly (2004), who also noted that residential setting was a more significant determinant of activities with friends than participant characteristics.

Al-Yagon (2007) found that children with ID manifested more socio-emotional and adjustment problems than their typically developing peers. Specifically, they reported higher levels of loneliness and lower levels of hope. Al-Yagon

suggested that this may indicate a lesser ability to cope in individuals with ID. The author goes on to say that the parenting resources of the mother (such as using fewer avoidant coping strategies and/or having low levels of anxiety as to their ability to manage "problem" behaviour) has a direct effect on the emotional status of the child; more effective parenting resources seem to induce less loneliness and act as a buffer against feelings of hopelessness in the child. Children with ID are likely to be better adjusted if the mother does not have an avoidant attachment style to the child and to others.

Like the above study, most relationship research in and outside the ID arena has been conceptualised in terms of attachment theory. Bowlby (1988) states that attachment is an integral part of human nature and is defined as any behaviour that achieves or maintains proximity to a person more able to cope with the world. Attachments arise from a need for safety, and a secure attachment relationship is thought to lead the child into a range of psychologically healthy developmental pathways. Attachment relationships are typically defined as "strong and enduring emotional ties, with a desire to maintain proximity with the attachment figure and anxiety when that proximity is threatened, a desire to use the attachment figure as a source of support under conditions of threat and as a secure base from which to confidently engage in other activities" (Bartholomew & Thompson, 1995, p485).

It has been suggested that co-morbidity of Autistic Spectrum Disorder (ASD) and ID is often associated with attachment insecurity (Rutgers et al., 2004). Some authors have proposed that a diagnosis of ASD affects attachment more

than a diagnosis of ID, and this may be attributable to the social and relationship difficulties in ASD. For example, Rutgers et al (2007) found that children with ASD were rated as least secure compared to children with ID and non-clinical controls. More specifically, children with ASD and ID were less secure than children with ID, and the children with ASD and without ID were less secure than children with ID. This is in direct contradiction to a historical review which concluded that the majority of the evidence pointed to attachment between children with ID and their caregivers being dulled, delayed or even absent (Blacher & Meyers, 1983).

1.2 Relationships in People Who Have Committed Offences

Wood and Riggs (2008) suggested that a negative model of the self rather than a negative model of others contributed to the link between attachment style and the committing of sex offences. In a preliminary study of attachment patterns in four types of violent and sexual offenders, it was found that all four groups were insecurely attached, suggesting this is a general vulnerability factor rather than specific to sex offenders. Offenders committing other types of offences were comparatively the most securely attached (Ward et al., 1996).

In an exploratory study to examine early experiences and attachment patterns in an incarcerated sample, Frodi et al. (2001) found an extensive over-representation of individuals who were dismissing of attachment and attachment-related experiences, which represented almost three times as many as in the general population. Additionally, there were no securely attached

individuals in the sample and a number of participants were unclassifiable or had histories that were unresolved with regard to severe early abuse/trauma.

1.3 People with Intellectual Disabilities Who Have Committed Offences

Although Johnston (2005) states that the belief that the presence of an ID predisposes criminal behaviour per se is no longer widely held, there is quantitative evidence to suggest there are common factors in the histories of people who offend (Isherwood et al., 2007). One of these factors is believed to be attachment (Marshall, 1993; Ward et al., 1996; Kenny et al., 2001). In a comparison of characteristics, referral patterns and outcomes, Lindsay et al. (2004) noted that sexual offenders with ID had a history of problematic family and romantic relationships when compared to other types of offenders with ID. Winter et al. (1997) found that, when comparing offenders with ID to their non-offending counterparts, over twice as many had experienced parental separation or divorce than in the comparison group.

To date, there is no published research on the relationship experiences of adult offenders with ID. It was decided that a qualitative inquiry would be most appropriate as it offers an opportunity to understand "how people interpret their experience, how they construct their worlds and what meaning they attribute to their experiences" (Merriam, 2009, p5). Not enough information is known about the practicalities or lived experience of relationships of people with ID to conduct a prescriptive, rigid survey inquiry, and this study will focus on a small number of semi-structured interviews to gain an in-depth understanding of the experience of relationships. Qualitative research "is pragmatic, interpretive and

grounded in the lived experiences of people" (Marshall & Rossman, 2010, p2), and therefore gives the research participant their own voice. Thematic Analysis (TA; described by Aronson, 1994) was considered most suitable to analyse the data as it focuses on identifiable themes and patterns of living and behaviour.

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Aim

To explore the relationship experiences of men with ID in secure settings.

2 Methodology

2.1 Ethical Approval

Approval was granted by the research and development departments of the host NHS trusts and by South Yorkshire Research Ethics Committee.

2.2 Participants

Participants were recruited from two secure units for men with ID. Eleven men who were detained within these settings were approached to take part in the study. Ten consented to participate and one declined, giving the reason that he did not want to talk about his past. All participants were adults aged 21 – 53 years (mean age 35.5). Participants had IQ scores of 59-75 (mean 67.5). All had been detained under the Mental Health Act (1983, 2007) following convictions for arson or violent or sexual offences (including manslaughter, wounding with intent, rape and indecent assault). Four were detained at a medium secure unit for men with ID and six at a low secure unit for men with ID.

Samples of this size are common in qualitative interview studies given the time-consuming nature of the analysis (Braun & Clarke, 2006). Four of the participants had a diagnosis of at least one major mental illness (including bipolar disorder, schizophrenia, depression, post-traumatic stress disorder and anxiety) as well as some degree of ID, and nine had diagnoses or traits of personality disorder (PD), most frequently anti-social or borderline.

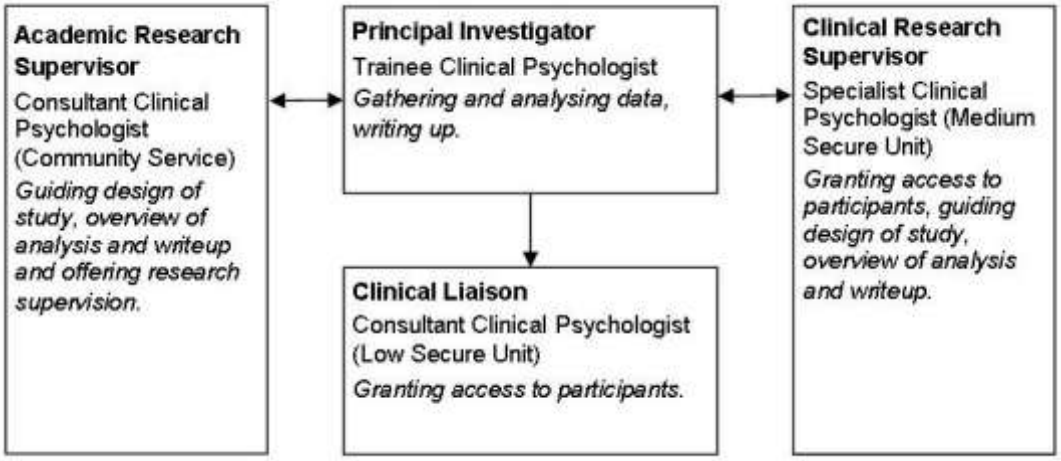
2.3 Researchers

The research team comprised three people: a trainee clinical psychologist from The University of Sheffield, a specialist clinical psychologist from a medium secure service for men with ID and a consultant clinical psychologist from a community service for people with ID. The first person listed was the principal investigator who gathered and analysed the data. The role of the other researchers was to guide the design of the study and to review the analysis (including 'credibility checking'). An additional clinical liaison granted access to further participants from a further site. Figure 3 demonstrates the structure of the research team. Participants were accessed through the clinical psychologists working in the two secure units.

The principal investigator is a white female in her twenties. She has an interest in working with and understanding people with ID and has conducted quantitative research within this client group in the past. She is currently on placement with a community ID clinical psychology and counselling service and has responsibilities in clinical interviewing, assessment and the delivery of psychotherapeutic interventions. Given this role and interest, the assumptions from the research are that a poverty of relationships will have been experienced by participants, with both a lesser quantity and quality of connections. Likewise, it is expected that participants may have had negative experiences with their peers, perhaps being bullied or left on the periphery of friendship groups, and that given the nature of their ID may have been exploited or abused at the hands of peers, partners and family carers. To ensure the analysis primarily reflects the narratives of the participants and not merely the researcher's

assumptions attention will be paid to validity and reflexivity and a diary will be kept by the principal investigator (see 2.8 and 2.9). This is not the principal investigator's first experience of undertaking a qualitative research project, but it is her first using TA.

Figure 3: The Research Team.



2.4 Recruitment Strategy

As is typical in qualitative studies (Saradjian et al., 2008), participants were selected through purposive sampling. The clinical psychologists working in the secure services were asked to select people whom they assessed as having capacity to consent to taking part in the research. Any individuals with acute mental health problems or active, unstable symptoms or those who were not considered to have capacity were not approached.

Each of the inpatients identified were approached by their psychologist and given an information leaflet explaining the aims of the research and issues of

confidentiality and disclosure. The consent form was also discussed with potential participants. Pictures and symbols were used throughout these documents, and information was broken down into short sentences and paragraphs to increase accessibility (See Appendix II). Potential participants were invited to ask any questions they may have about the study. At this point, participants were asked if they were interested in taking part, although formal consent was not sought at this stage.

2.5 Consent

After receiving the documents, each participant was given time and support from their nursing team to consider their participation. If potential participants expressed an interest in taking part, an individual interview appointment was scheduled for at least one week later. Understanding was checked at the interview appointment and the information sheet was revisited in the appointment prior to the commencement of the interview. The consent form was signed in the session by the participant and the principal investigator. All those who took part gave written consent.

2.6 Procedure

Each participant was interviewed in a suitable room within the unit where they were detained. Data were collected through semi-structured interviews (see Appendix III); the interview schedule was piloted on one participant to assess the suitability of the questions for this particular area of research. As no changes were made to the schedule following this pilot, the data from this

interview were integrated into the final analysis. Nine participants were interviewed once, with one being interviewed on two occasions at his request. The interviews lasted between 25 and 45 minutes (the two interviews for the tenth participant lasted 35 minutes in total). The interview schedule ensured that the following areas were covered:

- asking the participant to describe themselves, including their physical appearance, personality and interests and activities.
- family life including relationships with immediate family members when a child and as an adult and the experiences of growing up.
- other relationships outside the immediate family such as with wider family members and at school and college.
- more recent relationships with friends, partners and others.

A key aspect of semi-structured interviews is the extent to which participants have a role in shaping the direction and content of interviews (Smith & Osborn, 2004). As a result, events and encounters beyond relationships were covered in all the interviews, enabling a rich account of experience and identity.

2.7 Data Analysis and Rationale for the use of Thematic Analysis

TA was used to analyse the interview transcripts (Aronson, 1994). This methodology was considered most suitable as it is a method for identifying, analysing and reporting patterns within the data. TA is considered to offer “an accessible and theoretically flexible approach to analysing qualitative data...should be seen as a foundational method for qualitative analysis.” (Braun

& Clarke, 2006, p77). TA was chosen above other qualitative methods of investigation and interpretation such as Interpretative Phenomenological Analysis (IPA; Smith; 1995, 1999, 2004) and Grounded Theory (Glaser, 1992) as it is not grounded in, nor does it seek to produce, specific theory (Braun & Clarke, 2006).

Analysis was carried out by the principal investigator. The interviews were transcribed from the audiotape recordings; approximately half were done by the principal investigator, the others by a professional secretary with experience of transcription. Each transcript was then checked against the audio-recording for accuracy (MacLean et al., 2004). At this stage, each transcript was analysed in turn, separately. Each transcript was read several times and transcripts were annotated with initial thoughts on each meaning unit (Smith, et al., 1995). Each meaning unit was explored and ascribed a theme, with a clear and demonstrable link between the participant's words and the theme ascribed to them. The themes of each participant were then considered in relation to each other, generating clusters of subordinate themes based on their association.

A summary table was produced for each participant containing the clustered subordinate themes and quotations from the original transcript. Great care was taken to ensure that the themes reflected the meaning-making (Eatough & Smith, 2006) of the participant rather than just the expectations of the researcher. Once all ten participants had a summary table unique to them, the subordinate themes were then explored across the series, with master themes

being produced as a result. Finally, these master themes were grouped once more into superordinate themes. It is these wide-reaching superordinate themes that are used as a conceptual framework to understand this group of people (see Appendix III for an illustration of the analysis process).

2.8 Validity

While validity and quality are important aspects of qualitative inquiry, the traditional quantitative methods of ensuring studies yield robust and reliable findings are not appropriate. It has been argued that qualitative research should be evaluated according to recognised relevant criteria (Willig, 2001).

- To ensure construct validity in the present study, a pilot interview was conducted to ensure correct operational measures had been established (Yin, 1989).
- There are documented problems in the reliance on participant agreement to justify qualitative findings, such as social desirability and peer pressure when focus groups are conducted (Ashworth, 1993). In spite of the problems raised by Ashworth, he also indicates ethical and political reasons for the inclusion of participants throughout the research process. Participant validation was undertaken on an individual basis to attempt to minimise participant reluctance to disagree with peers, and to ensure their voices were heard throughout the data collection, analysis and writing duties.
- Reliability is concerned with allowing a third party to replicate the research and reach comparative results (Yin, 1989). The goal of this test

is to minimise errors and biases in a study, some of which are embraced in TA through the interpretative element, and the acknowledgement that it is not necessary – and is unrealistic – for a researcher to compartmentalise themselves away from the study (Smith et al., 2009). One important aspect of Yin's recommendations, however, is for a third party to audit the project. This relies on clear documentation and a visible audit trail. In this study the analysis has been subjected to an audit through the use of peer validation, and research supervision has provided a second eye throughout the research process.

- Although qualitative exploratory research is not concerned with generalisability, demographic information is provided about all participants for the reader to assess to what extent results can be considered within the wider population.

2.9 Reflexivity

There are several ways in which reflexivity and its component features are understood within the literature. The importance of this concept however is universal; reflexivity is an integral aspect of the openness and clarity required for valid, useful research (Merrick, 1999).

Merrick (1999) considers this meta-reflection to have three components: personal reflexivity, functional reflexivity and disciplinary reflexivity. *Personal* reflexivity is concerned with the researcher's acknowledgement of who they are and the beliefs and biases that influence the research from conception to

completion. *Functional* reflexivity refers to the continuous critical examination of the process of the research project and *disciplinary* reflexivity involves reflecting on wider issues within psychology and beyond.

Willig (2001) understands there to be just two types of reflexivity. Personal reflexivity is almost identical to Merrick's, with an exploration of how the research process may have impacted upon the investigator as a researcher and as a person. Epistemological reflexivity encompasses both functional and disciplinary reflexivity, and encourages researchers to reflect upon the assumptions that have been made in the course of the research and the implications of such assumptions for the research and its findings.

Nightingale and Cromby (1999) state that reflexivity demands us to "explore the ways in which a researcher's involvement with a particular study influences, acts upon and informs such research" (p. 228), and Carolan (2003) understands reflexivity as the way in which the researcher impacts upon the data collected, and the critical evaluation of that impact. This follows the understanding that "all findings are constructions of one's personal views of reality" (Merrick, 1999, p.23) and as such, a reflexive journal was kept by the principal investigator to attend to personal and functional reflexivity. Epistemiological and disciplinary reflexivity are considered in the discussion section by examining the way in which this research supports and extends current theoretical knowledge. Finally, personal information about the principal investigator is provided earlier in section 2.3.

3 Results

This exploratory study was interested in people's experiences of relationships throughout their lives. Analysis of the transcripts revealed three superordinate themes: 'interpersonal factors', 'the internal-external interface' and 'safety'. These are presented below in Table 2, along with subordinate themes. Each superordinate theme is described in turn, along with supporting quotes from the original transcripts. The thematic hierarchy is displayed in the table. In order to preserve anonymity, where participants have used names to describe people, these have been changed. Where places are identified, these have been replaced by the symbol {XXX} in the text. Some of the quotes used are followed by an explanatory remark in parentheses to help the reader understand context. Where text has been omitted due to being superfluous it is identified with this symbol {...}. Each quote is followed by a comment identifying which participant the quote is taken from and whereabouts in the transcript the quote occurs.

Between 7 and 12 quotes (mean 9.4) were selected from each participant to illustrate the findings. This ensured each participant had a voice in the analysis, emergence of key themes and the write-up itself. Quotes were chosen if they encapsulated a theme particularly well, and are provided for the reader to consider the evidence behind the clustering of the themes. The two participants with 12 quotes had longer interviews and therefore contributed to more of the sub- and super-ordinate themes.

Table 2: Compositional Structure of Themes (code represents thematic hierarchy).

Thematic Level	**Code**	**Theme 1**	**Code**	**Theme 2**	**Code**	**Theme 3**
Superordinate	1	Interpersonal Factors	2	The Internal-External Interface	3	Safety
Master themes	1.1	Relational Processes	2.1	External locus of control	3.1	Protection
	1.2	Challenging Behaviour	2.2	Occupation	3.2	Vulnerability
			2.3	Sense of self	3.3	Lack of knowledge
			2.4	Consistency		
			2.5	Boundaries		
Subcategories	*1.1.1*	*Growth/ repair*	*2.1.1*	*Reliance for permission and decisions*	*3.1.1*	*Being protected*
	1.1.2	*Rupture*	*2.1.2*	*Reliance on others' availability*	*3.1.2*	*Protecting others*
	1.1.3	*Maintaining friendships*	*2.1.3*	*Externalising of responsibility*	*3.1.3*	*Protecting self*
	1.1.4	*Isolation*				
	1.1.5	*Rejection*				
Subcategories	*1.2.1*	*Externally maladaptive behaviour*	*2.2.1*	*Treatment to improve*	*3.2.1*	*Abuse*
	1.2.2	*Internally maladaptive behaviour*	*2.2.2*	*Treatment to impress*	*3.2.2*	*Bullying*
	1.2.3	*Stable behaviour*	*2.2.3*	*Lack of interests*	*3.2.3*	*Exploitation*
					3.2.4	*False accusation*
Subcategories			*2.3.1*	*Self-image*	*3.3.1*	*Lack of recall*
			2.3.2	*Feeling overwhelmed*	*3.3.2*	*Lack of information*
Subcategories			*2.4.1*	*Stability of contact*		
			2.4.2	*Stability of placement*		
			2.4.3	*Stability of relationship*		
Subcategories			*2.5.2*	*Consequences*		
			2.5.1	*Discipline*		

3.1 Superordinate Theme 1: Interpersonal Factors

3.1.1 Relational Processes

The first superordinate theme relates to relationships, and the processes through which they are established, maintained and threatened. Given the nature of the interview questions, it is unsurprising that this theme occurred across all participants.

3.1.1.1 Growth and Repair: *"when I got older I seemed to get on with him"*

A common subordinate aspect of this category was growth and repair, and the acknowledgement that relationships can change as a result of the process of maturity and personal development:

> *"Has your relationship with your mum always been really really good?"*
>
> "No. Bad. I've never got on with my mum until I left home that I realised how much I love her." (Ben, 88-90, speaking about how his relationship with his mum is now "really really good", and the interviewer's follow-up question using Ben's own words to ask if that had always been the case).

> "Well she she she was a bit strict mother but as it's gone on it's got tolerant but as it's gone on it's got like more understanding she like she like can't take't strap to me no more but she can sit down and talk to me." (Luke, 130-132, reflects on the change in his mother's reaction to his challenging behaviour).

Here, Luke seems to struggle to find the words to describe the shift in their relationship, and is unable to define the intangible qualities that make a good relationship.

Both Des and Nick speak about the death of a parent and the subsequent relationships of their surviving parents.

> "I wasn't happy...I just got on with it I just had to accept it." (Des, 329, talking about his mother getting remarried).

> "Shortly after my dad met my stepmother and eventually, it took a while but eventually we started getting on with each other." (Nick, 108-110, talking about his father's marriage to his new wife).

While Des acknowledges he wasn't pleased about the relationship he reached a level of resigned acceptance. Nick recognises that although it took time for him to form a relationship with his father's new wife, their relationship did develop into a good connection, hinting at former tension.

3.1.1.2 Rupture: *"we were always arguing, fighting, carrying on".*

This tension and following ruptures were spoken about by all participants. Greg said there were "arguments all the time" (55) at home, Ryan noted "me and my adoptive mum never got on" (241). Des also said "there were fall outs" (182) between him and his sisters and parents and Rob admits, after stealing from his family to fund his substance use "my brother never trusts me again" (244).

3.1.1.3 Establishing and Maintaining Relationships:

"even wi' every up and down, we're still friends".

Participants found it difficult to quantify the methods used to establish and maintain relationships, including friendships. Steven notes "only way I can find out relationships is mixing is mixing with people more and get to talk and…" (528-529). Here, Steven has a goal to spend time with other people to make friends, but he repeats himself and is unable to finish his sentence. Perhaps this reflects a lack of confidence in his ability to make friends, and an attempt at eliciting reassurance or advice. Within participants' accounts there was also an ambiguity in what made a good relationship, and how these were distinguished

> "'Cause I don't cause them any trouble and they don't cause me any trouble. Do you know what I mean, that's probably the easiest way you can do it. Do you know what I mean?" (Greg 259-261)

> *"So what makes the ones that you get on with, what makes them better?"*
>
> "They talk to me and we have a laugh. Play on't computer together. Go out together. That's it really." (Ben, 505-509, during a conversation about who he spent time with on the unit, and his reflection that he only socialised with some of his peers)

> *"*Err I have a laugh with them." (Rob, 165-172, responding to the same question as Ben above).

Here, Ben and Rob demonstrate the use of humour as a bonding tool, and of shared joking as a means of maintaining a connection. Des speaks about finding himself in a partner relationship and wanting to maintain it "She asked me if I'd go out with her I said yeah. So I did. I started a relationship and I wanted to keep it going" (55-56). His not going into detail about how he tried to maintain the relationship (which was short-lived) perhaps betrays his lack of experience and skills in this area.

3.1.1.4 Rejection: *"they kept putting phone down on me".*

In addition to these positive and indefinite experiences there were problems in relationships, and many participants experienced rejection from partners, family members and also from systems:

> "I went to about 6 schools in about 3 months just kept getting moved from school to school to school 'cause like I couldn't cope. They couldn't cope, you know, and they didn't know what to do with me in school, so they just kept moving me to different schools all't time." (Greg, 173-177).

Here, Greg tries to rationalise why he was subjected to recurring expulsions. His confused account of both he and the schools being unable to cope possibly indicates a lack of understanding of the process and of trying to make meaning and intellectualise the negative feelings associated with repeated rejection.

3.1.1.5 Isolation: *"I've never had real friends".*

Isolation was a common subordinate theme. It is hypothesised that these feelings of solitude were a product of the negative experiences in intimate relationships with partners and from the repeated transfers and expulsions from school. Rob and Andrew speak about self-imposed isolation, which appeared to be an attempt to protect themselves from further emotional trauma:

> *"Do you get on with any of the other patients?"*
>
> "I err don't really bother with them keep myself to myself." (Rob, 209-210).

> *"What about friends?"*
>
> "I just like to keep myself to myself." (Andrew, 362-363).

Steven's isolation was as a result of the death of his parents and due to a lack of other family or friends. He found himself alone and with an extreme sense of loss when his parents passed away;

> "I couldn't believe it my mum and dad died you know what I mean 'cause they were only only friends I had" (125-126).

3.1.2: Challenging Behaviour

Another aspect of the interpersonal superordinate theme was challenging behaviour directed towards others or the self. Challenging behaviour has been considered part of the interpersonal theme as whether or not the intended result

is an activation or termination of behaviour by another person or system, this is often a consequence.

3.1.2.1 Externally Maladaptive Behaviour: *"I used to go and hurt people".*

Externally maladaptive behaviour, concerned with challenging the environment, was spoken about by all participants as they contemplated their offending histories:

> "I had bad mood swings, I used to smash things and stuff like that. I used to run away a lot. I used to do all sorts of things. I used to commit commit offences. Serious offences and stuff like that." (Andrew, 146-148).

And attention was paid to rule-breaking in school and at home:

> "I didn't used to do anything I just used to sit in the corner all day doing nowt and causing havoc in school." (Greg, 184-185).

> "I were just like picking bottles up and smashing windows and kicking bins over." (Nick, 178).

> "Smash doors, erm, put windows through. All sorts." (Ben, 27).

As a way of avoiding difficult situations, many participants tried to escape. Greg recalls he would "Go out. Or go upstairs" (102) whenever his parents argued, and Rob would attempt to outrun his mental health problems; "when my head were upset my head I'd run off" (180-180).

3.1.2.2 Internally Maladaptive Behaviour: *"I tried to kill myself".*

As well as challenging behaviour directed outwards, Nick, Greg and Ryan also self-harmed as a way of coping with challenging emotions, with Ryan stating that burning his arms with cigarettes was "just to relieve pain" (534).

3.1.2.3 Settled Behaviour: *"I'm a well behaved person now".*

In contrast to these episodes of challenging behaviour, some participants spoke about feeling settled at the moment. Nick in particular proudly stated "I've never kicked off, you know. Basically 'cause I don't see no point in it" (6-7) right at the start of his interview, and Steven hesitantly stated "I think my behaviours have been settled now, and I think I'm finding it ok now" (22-23). It is interesting to note that some participants declared themselves as "settled" at the start of the interviews; this was perhaps an attempt to build rapport and a way of making the interviewer feel at ease. Alternatively it could be an uncomfortable necessity given their history of violent acts and sexual offending.

Summary

All participants experienced multiple rejections, and many isolated themselves in an attempt to avoid further hurt. Despite this, there was a recognition that relationships can change for the better as people develop and their outlook changes. All participants displayed challenging behaviour in their past, but there was a sense that they too had become more settled. The primary way in which friendships were maintained was through humour, although it was seemingly difficult for participants to identify the good aspects of relationships.

3.2 Superordinate Theme 2: The Internal-external Interface

This superordinate theme refers to the interaction between factors in and of the person and characteristics or behaviours of other people or their environment. For example, this theme encompasses master themes of locus of control, boundaries and consistency. Such aspects of life are neither inherent to the individual nor simply products of the behaviour of the environment and others within it – including wider society and its values. For meaning to be made, there has to be an interface between the individual and those around; a reciprocal exchange where one is impacted upon by others and their rules, availability and the opportunities they present, and where one responds and impacts on those around them.

3.2.1 External Locus of Control

External locus of control refers to the sense that participants felt they had no control over their actions and the course of their lives. Within this was an awareness of dependence on and restriction by others, not, as one may expect, related to the participants' ID, but by virtue of being detained.

3.2.1.1 Permission and Decision-making: *"it's a bit like prison".*

There was a clear sense of a reliance on others for permission – "sometimes they won't let me spend what I want to spend" (Andrew, 68, reflecting on restrictions in the amount of money he is able to spend on any one shopping trip) – and in waiting for others to make decisions "I didn't think it would ever come. You know, time just seemed to be passing and just wouldn't stop" (Nick

considers the time he has spent in secure services and the wait he has until he can be transferred to a stepped-down service). Steven regretfully notes that when his mother died, “the nurses told me...but I couldn’t get to her because there was no transport no staff to take me” (117-120). Des looks forward to the future, where he will have more control over his preferred activities, such as being able to go out to dinner “[when I am] out in the community if they get an house and I lived there I could go out at night time and do things like that” (612-613).

3.2.1.2 Others’ Availability: *“he’s always busy, you see”.*

In further recognition of the constraints of being detained, there was a sadness regarding reliance on the availability of others. Daniel reflects on the lack of physical contact he has with his daughter (who he speaks to regularly on the telephone); “I can’t [see her] because she’s 17. She’s got to be 18 [to visit the unit]” (238), and his young sons (with whom he has no contact); “my mum says “they’ll want to know you when they’re older” so just wait til then” (251). Furthermore, there is a reliance on others coming to visit, and a sense of waiting for them to prioritise contact. Andrew sees his brother “not very often...because he works most of’t time” (115).

3.2.1.3 Externalising of Responsibility: *“she put me in here”.*

This externalising of responsibility was a key feature of the accounts of many of the participants, with many blaming their offending behaviour on the actions of others, their mental health problems or their parenting.

> “My dad used to put doors through. That’s what made me/I think that’s why I’m like got partly a bad temper ‘cause through my dad” (Ben, 208-209),

> “Well I were drunk at the time...really drunk out my head and I didn’t feel very well neither... they’d given me an injection and I started getting bad side effects off the injection” (Andrew, 332-335, talking about his second index offence that he committed whilst absconding).

> “now I’ve got a girlfriend I don’t really have to stalk women no more” (Luke, 15, considers his relationship with his girlfriend a protective factor against future offending).

While it is possible that the behaviour of Ben’s father had an effect on his own tolerance to being frustrated and Andrew’s schizophrenia and medication may well have affected his perception and judgement, there is a clear externalising of responsibility for their actions (Weiner, 1985). Luke clearly believes he offended out of necessity; he wanted a partner and felt he had no other means to establish such a relationship. This perhaps supports the findings in 3.1.1.3 that people are unsure how to instigate the relationships they crave.

3.2.2 Occupation

Participants spoke about life on a secure unit, and of the activities and scheduled sessions that are available to fill the time. All participants were offered a timetable of treatment sessions including occupational therapy, community access, individual therapeutic sessions with their named nurse, psychology sessions, group work and all had an allocated "special interest worker"; an unqualified nursing role designed to increase the pursuit of appropriate activities.

3.2.2.1 Treatment to Improve: *"my personality has changed".*

Most of the activities that were available to participants centred around treatment, and many spoke of interventions that are available to them. There was a split in the sample, with approximately half talking about the value of interventions and the hopes they gave them for the future.

> "'Cos I haven't got much self esteem or confidence so. Hopefully it'll give me some. You know?" (Nick, 33-34, hoping to gain life skills and achieve more from treatment above and beyond release).

> "Doing things like that that I shouldn't be doing but I'm getting help for it now, getting help getting help getting help for it now so yeah." (Steven, 83-185, talking about his criminal history as a sex offender, and his investment in treatment to have a different future).

3.2.2.2 Treatment to Impress:

"I tend to do all my sessions, 'cause it goes good for you in the long run".

The other half of the sample had different ideas regarding the purpose of treatment. Within these participants there seemed to be a resignation that treatment would be ineffective, but that to secure release an element of compliance was necessary:

> "I just find it a bind at the moment. You know, just doing everything to please everyone and not pleasing myself." (Daniel, 370-371).

> "I always do things that they wanted me to do." (Likewise, Des, 404).

Daniel speaks about his lack of faith in the interventions offered to him, and a sense that his own agenda and that of the nursing team and wider system are incongruent. Likewise, Des reveals that he considers himself restricted by his sisters' expectations and demands, and that he has a lack of opportunities to pursue his own agenda. The confusing of tenses in Des' account may reflect a long-standing desire to please his sisters and make them proud of him that continues to the present day. Earlier in his interview he revealed that his sisters had encouraged him to engage with treatment on the unit, stating "we don't want to be unproud of you we want to be proud of you" (368-369). Des does not appear to have the same command of the English language as the other participants, perhaps reflecting his diagnosis of psychosis or his comparatively low IQ. His interview transcript was confused, and there was a sense that he

wanted to “get everything out”; the manner of some of his disclosures felt more suited to a therapy session than a research interview.

3.2.2.3 Lack of Interests: *“it’s boring, but it’s alright”.*

The pursuit of interests was limited to those activities that had been risk assessed and could be engaged in while detained. As a result, the analysis highlighted the lack of interests and boredom in some participants. There was a sense from many respondents that they had not been given or had not taken the opportunity to consider what their interests might be:

> *“And what about on the unit what kind of activities do you do?”*
>
> “Not much just get bored.”
>
> *“What is there to do?”*
>
> “Not much watch TV and play pool and sometimes I get bored of ‘em and I start getting a bit funny.” (Rob, 42-46).

Here Rob indicates that he sometimes displays challenging behaviour, and he externally attributes this to boredom on the unit. This is congruent with the external locus of control outlined in section 3.2.1.3

3.2.3 Sense of self

For all participants, there was a period of self-reflection and consideration of their own identity. This theme encompasses self-image and feelings of being overwhelmed.

3.2.3.1 Self-image: *"I've got blue eyes and err cheery an err ahhh..."*

The majority of participants had difficulty in describing themselves, with frequent use of "I don't know", stilted descriptions peppered with "err", and many asking for reassurance that they were capturing themselves accurately.

> "I don't know. Erm (pause) sense/good sense of humour. And erm (pause) I don't know really. I always get asked that question and it's always hard to answer 'cause I don't know." (Greg, 2-4).

> "Errr, caring. I don't know really, caring, err, trusting, that's about it really... Fun, happy, outgoing, that's it really." (Daniel, 3-5).

This lack of confidence in their descriptions may demonstrate a lack of self-assurance that characterises their lives. Greg revealed that he had been asked this question a number of times before, and despite these opportunities to consider how he sees himself he was unsure of his response, and seemed unable or unwilling to fully engage with the question. Perhaps Greg and Daniel had experienced invalidating environments, or been repeatedly told that their opinions were not valued. In line with this, some participants had a negative view of themselves or identified themselves by their mental health or anger problems:

> "Mental health problems. I've got lots of mental health problems. I've got personality disorder. I've got schizo-affective disorder

borderline type. Errr I've got moo mood swings as well." (Andrew, 3-5).

"I just think that I'm ugly. Fat. I think that's it." (Ryan, 29).

For Ryan, this negative self view appeared to be all-encompassing. It seemed there was always something he felt he could have done more of, or better, and this seemed to prevent him from fully acknowledging and celebrating his successes; "I only got G in English, the rest of the subjects I failed on." (131).

3.2.3.2 Feeling Overwhelmed: *"I'm finding it difficult to cope".*

Participants spoke of feelings of being overwhelmed, both in terms of themselves being unable to cope with their environments; "Can't cope with sommert like…I've got over it now but it took me a long time" (Rob, 258, speaking about the death of his cousin, whom he treated "like a daughter") and of others being unable to cope with their challenging behaviours; "I was self-harming, and my adopted mum and dad couldn't cope with me" (Ryan, 146-147, reflecting on the impact of his behaviour onto his adoptive parents). Luke, however, is proud that his outbursts following disagreements with staff are short-lived, "just 5 minutes it wears off you know" (282).

3.2.4 Consistency

Consistency was important for participants, with some talking about the value of reliability and routine. This consistency was discussed regarding stable family

contact, the stable or transient nature of school and hospital placements, and the transiency of romantic relationships.

3.2.4.1 Stability of Contact: *"I go home once a month".*

There was an appreciation of consistency of contact with others, with Rob citing contact with family as a reason for his transfer to his current placement; "I'm always home. That's why I moved to XXXX" (323-327). Luke highlights the importance of maintaining contact with his mother and the mutual effort that is made; "I see my mum once a month here, I am on phone here every day here and if I've got a free period I'll go and see her" (Luke, 97-98).

3.2.4.2 (In)Stability of Placement: *"I've been in hospital a long time".*

As well as contact with family, stability and instability of current and previous placements were discussed. Andrew laments his 29 year stay in secure settings, and acknowledges that he no longer has awareness of what it is like to live in the community; "I don't know. I don't recognise anything any more. I don't know any different" (168). For some participants there have been a series of moves throughout their lives; schools, hospitals, prisons and secure units have all moved them on:

> "So I were moved around a lot into battered wives' hostels" (Daniel, 51-52, speaking about domestic violence perpetrated on his mother by his father when he was growing up, and the consequences it

had on him and his siblings as they were taken to a series of hostels).

"School were bad. I were in and out of school. I've been to about 15 schools" (Ben, 239).

"Then I went from XXXX back into hospital in XXXX where I was only there for a week. Moved from XXXX to XXXX." (Ryan, 151-153).

3.2.4.3 Instability of Relationships:

"I've had a couple of girlfriends but they never lasted long".

Finally, there was consideration of the transiency of some relationships, particularly romantic ones:

"Most I've had a girlfriend for is 1 month up to 2 month" Rob (232-233).

"I, well, other relationships have just been (pause) well they've been good but they've just not last long" (Nick, 255-256).

There was a sense of regret from the participants that mentioned partners that these relationships fell apart, and a tentative hope that relationships in the

future would be more successful. Greg and Rob both said they wanted to get married and have children in the future.

3.2.5 Boundaries

Boundaries were mentioned by some participants, with discussions revolving around discipline at home and school and the consequences of bad behaviour. There was a stark contrast between what was seen as insignificant attempts at discipline and the grave consequences of their actions; particularly those imposed by the police and criminal justice system.

3.2.5.1 Discipline: "*he's soft with me*".

Many participants paid attention to discipline, particularly when referring to a lack of discipline, or of discipline that was not taken seriously:

> "I never got punished or there were no discipline or I never got punished, so... It just gave me an open window to do anything" (Greg, 67-77, reflecting on a lack of punishment from his parents for bad behaviour).

> "Yeah (laughing) they used to they shouted at me" (Rob, 154, recounting a time he was taken home by the police after being caught shoplifting).

3.2.5.2 Consequences: *"I went to prison".*

Some parents did apply consequences, with Nick struggling to recount his mother's reaction to him being arrested for public order offences when he was a teenager; "She went thingy, shouting at me all the time" (186). At this stage of Nick's interview he went quiet for a few moments, perhaps reflecting on the impact his behaviour had had on his mother and or their relationship. Other consequences were applied by the police – "so he took my knife off me" (Luke, 155, recounting his birthday present being confiscated by a police officer after he was found with it in the street) – and the Crown Prosecution Service; "I actually got locked in a prison for it" (Rob, 135, talking about a drunk and disorderly arrest).

Summary

Many participants experienced a lack of meaningful activities to fill their day beyond treatment, and had mixed opinions on the value of interventions. Participants displayed an external locus of control with regard to their offending behaviours and a dependence on others for decision making. All participants struggled to describe themselves and showed a lack of confidence in their descriptions. There was a shared experience of multiple transitions from placements and an acknowledgement of the importance of stability in contact with family. Most had experienced fleeting romantic relationships. There was a sense that parental discipline had not been meaningful for participants but that the consequences of their actions had greater impact, particularly when applied by the justice system.

3.3 Superordinate Theme 3: Safety

3.3.1 Protection

The final superordinate theme identified in the analysis was safety, an element of which was protection by others.

3.3.1.1 Being Protected: *"both of 'em look after me".*

Participants appeared to value being cared for, and also the sense of being validated and important when people looked after them:

> "my mum went to their house once when I was covered on legs in bruises once so my mum went to their house and walloped him one, walloped son like for doing it to me like and yeah, picking on me." (Steven, 457-460, reflecting on his relationship with his mother and how she attempted to rescue him from being bullied).

Likewise, Luke recounts his father saving him from drowning when he fell into the river:

> "I couldn't swim very well, and I fell in that and he dragged me out." (145-146).

Some of the participants spoke about being parented by older siblings because their parents were unable to care for their children themselves:

> “Well when I were a kid it were my sister who looked after me.” (Nick, 202).

And Ryan stated:

> “When I went to school in XXXX I had a mate called John Jones who taught me how to ride a bike” (369-370).

3.3.1.2 Protecting Others: *“I were like a dad to her”.*

This parentification (Jurkovic, 1997) went both ways, with some participants recounting times they had to look after for their younger siblings:

> “Just look out for them and sort of like help them clothe theirselves and make sure they had something to eat and went to school and stuff.” (Daniel, 74-75, explaining how he looked after his younger brothers when the family had fled to “battered wives’ hostels”).

> “I was trying to be brave for my brother ‘cause my brother were crying his eyes out.” (Ben, 195-196, remembering his attempts to comfort his younger brother whenever their parents argued).

Luke has a girlfriend who also has an intellectual disability. Luke is more able than her, and he considers part of his role to make sure she is not put into situations she cannot manage.

> “We haven’t been to pictures yet you know I don’t know if she can sit through films and that if she’s in a giddy mood ‘cos she’s out she might spoil herself you know” (216-218).

3.1.1.3 Protecting Self: *“I don’t see my dad... ‘cause he’s a druggie”*

Finally, there were times when participants prioritised themselves and protected their own future:

> “All my mates and that are all doing the same thing, you know they’re still taking drugs and they’re still doing crime and I don’t want to be dragged back into all of that.” (Greg, 247-249, states his reasons for actively seeking release into a different community to the one in which he grew up as a means to avoid relapsing into substance misuse and criminal activity.)

> “I’m more wise now though how I pal with anyone, you know?” (Luke, 245-246, speaks of his desire to remain out of trouble following his release into the community, and his recognition that a criminal peer group will not help him to achieve this goal).

3.3.2 Vulnerability

Within this superordinate theme of safety was recognition of the vulnerability felt by most of the participants. The product of this vulnerability took the form of abuse, bullying, exploitation and being unable to successfully defend the self from false accusations.

3.3.2.1 Abuse: *"I used to get badly abused".*

Many participants spoke of abuse, most commonly perpetrated by those charged with caring for them. Ryan disclosed that his foster parents "used to put salt up my nose...if I picked it" (186-187), and Nick stated "I was abused but not just/like hit by my dad like" (230). Nick appears to emphasise he was "just" hit by his dad, perhaps minimising the regular physical assaults perpetrated on him by his father or representing an idealised view of his parent.

3.3.2.2 Bullying: *"I was getting terrorised".*

Bullying was also a key feature, with the majority of participants being bullied at some stage:

> "I had a really bad childhood. I got beat up a lot."
>
> *"Who by?"*
>
> "School kids." (Rob, 83-85).

> "I err there were this lad he set my hair on fire with a lighter."
>
> (Andrew, 367-368).

Daniel recounts being both a perpetrator of bullying "I sort of like seemed to be't bully at school. Bully lads and that" (124-125, speaking about primary school) and a victim "got picked on... by all the lads and lasses" (133-134, in secondary school).

3.3.2.3 Exploitation: *"I felt like they were buying me"*

As an extension of the bullying there was a sense of exploitation, which seemed to be more of a feature of adulthood. Certainly Nick tells of a time when his partners would take advantage of him "I was always like going out you know trying to earn some money and I'd come back and they'd say "oh, can you lend me this" and that" (241-243), and Andrew notes that he reacts badly to people attempting to manipulate him, and appears to struggle to articulate himself "It's a bit it's a bit disgusting sometimes how how how some people treat you" (243).

3.3.2.4 False Accusation: *"It turned out to be my brother!"*

Some participants were accused of things that they had not done, and they reflected on the injustice of this and their lack of power to convince people of their innocence:

> "But when he come with his girlfriend he accused me of sleeping with his girlfriend and trying it on with his girlfriend and I weren't even doing nowt." (Ben, 160-162, being accused by his father of attempting to sabotage his relationship).

3.3.3 Lack of Knowledge

Finally, there was an awareness of participants throughout the interviews that there were pieces missing from their histories.

3.3.3.1 Lack of Recall: *"I can't really remember, 'cause I was too young".*

There was an overarching lack of knowledge that appeared to often result from a lack of recall:

> "I can't even remember when they first got together." (Greg, 112-113, speaking about his mother's relationship with his stepfather).

> "I can't remember owt else apart from that." (Steven, 245, attempting to tell me about his childhood and being unable to remember anything other than receiving presents from his parents at Christmas).

This lack of recall is often found in therapeutic work with people with intellectual disabilities. These patients often become confused with their chronology, and it can take a number of sessions before an accurate timeline is pieced together by the therapist (Prosser & Bromley, 1998). This poverty of recall may indicate repression of difficult experiences (Newman & Beail, 2010), or may indicate some reluctance to fully engage with certain aspects of the interview.

3.3.3.2 Lack of Information: *"I never knew".*

In addition to the above the participants here seemed to identify a lack of information, which would obviously affect their ability to recall events and the impact of these. Ryan is unsure of his diagnosis, and in the short time of one research interview, it is impossible to know whether this is due to mis-

information, an absence of information or difficulties in memory “Split personality disorder...I don’t know what one is” (5-7).

Finally, there was reflection by some participants that the information given to them was perhaps not always accurate. Ryan again talks of reading his life story book before he got back in touch with his birth parents and how intimidating that was because “I don’t know what to expect, ‘cos the life story said a loads of lies” (103-104).

Summary

All participants had experienced bullying, exploitation or abuse, and some had been perpetrators. This sense of vulnerability was encountered as a result of being in a position of reduced power, such as being placed into care. There was a sense of incoherence in the histories of the participants, which may have been due to a lack of information, repression of difficult experiences or unwillingness to elaborate in the research interview.

3.4 Participant Validation

Of the ten participants who were interviewed, 8 were invited to discuss the findings. The other two were experiencing a worsening of their mental health symptoms and their nursing staff requested they not be approached. The 8 that were asked consented to an individual meeting where all the superordinate themes and their subcategories were discussed. Many of the participants were eager to refute the subordinate themes that did not apply to them, and all clarified the themes that did apply to them. In particular, Des, Greg and Steven

all spoke about *lack of recall,* with Greg revealing that at times he had said he couldn't remember things as a way to close that line of enquiry down. Des appropriately acknowledged that the research interview was very different to a therapy session, and although he had been as open as he felt he could be there were things he too did not want to elaborate on. Steven, though, considered his occasional lack of recall as a function of not knowing what was happening at times in his childhood, or not fully understanding the reasons for occurrences such as family arguments or his own behaviour.

While the participants agreed that the majority of the subordinate themes characterised them accurately, this cannot be taken as absolute evidence that the findings are "correct". The themes reached were found through a course of meaning-making both by the participants in the interviews and by the principal investigator through the analysis, and as stated earlier, participants may agree with findings that they think are inaccurate for a number of reasons (Ashworth, 1993). This does not appear to be the case here, as all identified themes they did not believe applied to them. Whether or not the act of participant validation validates the findings, ethically it remains an important research task. All were interested to hear the results and take some ownership of the study they had dedicated their time and experiences to.

Between the interview and validation phase, Daniel had progressed from medium to low security. As a result the validation appointment took place in his new unit and Dr Wood (his former psychologist) sat in on this session. Dr Wood

noted that the research results mirrored the disclosures made by Daniel in therapeutic sessions, and that the research interview appeared to be akin to an accelerated assessment. If not adding weight to the validity of the results, it confirms that Daniel divulged the same information to the principal investigator in his interview as he did in therapy.

3.5 Full Results Summary

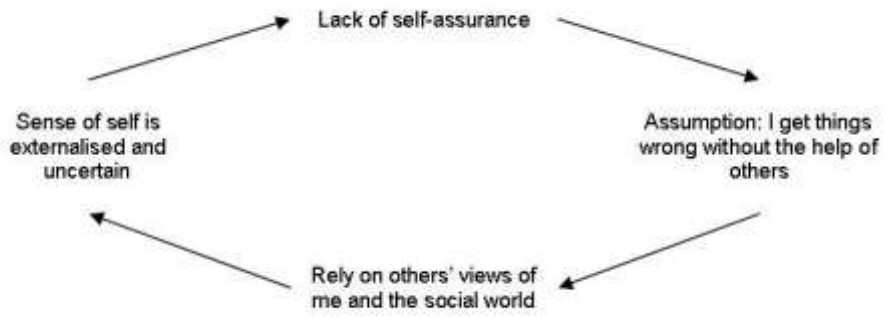
All participants described their experiences of relationships and of life in their own words. All the interview transcripts contained “rich data” – detailed descriptions leading to an insight into what life is like for them. Multiple themes emerged from every transcript, with a high amount of agreement and overlap. Participants painted a colourful picture of being a little on the outside of things, of being vulnerable and of relying on others above and beyond what they felt necessary and comfortable. As a result of these things participants felt low in confidence and were left with negative self-opinions. In spite of this adversity, many spoke of positive experiences of relationships, their own settled behaviour, encouraging response to treatment while in hospital and hopes for their future lives.

4 Discussion

4.1 Summary of findings

The analysis yielded three superordinate themes; “interpersonal factors”, “the internal-external interface” and “safety”. Perhaps one of the most illuminating themes was the lack of identity felt by the vast majority of participants. In this study it is theorised to be a result of a lack of self-confidence that characterises the participants’ lives (see Figure 2). This incoherent sense of self affects all relationships – including one’s relationship with oneself and potentially impacts upon any therapeutic work undertaken to address mental health problems. Another crucial aspect was self-induced isolation, a mechanism to protect participants from further negative experiences in relationships. Perhaps this is due to a negative view of the self borne out of a lack of validation and reassurance from others, and resulting in remoteness and feelings of inadequacy.

Figure 2: The Uncertain Sense of Self



There was a deep sense of powerlessness, not through the reduced cognitive and social functioning necessary for a diagnosis of ID but by virtue of being

detained in secure settings. Finally, it was interesting that a number of the participants announced themselves as "settled" towards the start of the interviews, perhaps as a way of building rapport or assuring the principal investigator that it would be safe to spend time with them on an individual basis. The latter would serve to reinforce the negative view of oneself; their forensic and mental health histories necessitate this declaration of being able to behave appropriately.

4.2 Links to Previous Research

Al-Yagon (2007) found that children with ID reported a lower level of hope, however the participants in this study did have hope for the future. Perhaps this is due to their repeated exposure to psychological and social interventions and a belief in treatment. Merriman and Beail (2009) found that when clients were asked about their experience of therapy, a sense that they were dependent in their relationship with the therapist emerged. Perhaps these findings support the problems of diagnostic overlap between ID and dependent PD raised by Lindsay, et al. (2007), and fit with the findings in the present study of being dependent due to restriction. Perhaps this security restriction masks a more inherent dependency that is demonstrated in non-forensic populations.

It has been shown that professional caretakers can become attachment figures for children with ID (de Schipper et al., 2006), and the current study lends support for this attachment in adulthood and has implications for the relationships between nursing staff and patients in secure settings. As

Merriman and Beail (2009) found, within the therapeutic alliance a secure attachment – albeit with the client in a passive role – facilitated productive therapeutic work. It is hypothesised that this would extend to other relationships within the multi-disciplinary team, and in this sample people appreciated available staff who responded in a predictable, validating way and took their problems seriously.

As Clegg and Sheard (2002) found that insecure attachment can predispose an individual with ID to challenging behaviour, working with children and families on attachment related problems at an early age may reduce the frequency and intensity of rule and law breaking as adults. This may work as a protective factor against imprisonment and secure hospitalisation. Indeed, all the participants in this study explicitly spoke about problems in their relationships with their parents. These relationships in many cases improved as the participants matured, although in some instances this repair was triggered by incarceration or the process of therapy. Providing support to children and the families of children with ID to help build and maintain relationships may facilitate the personal growth that has been shown to be necessary in this study for improved relations.

Although many participants spoke about isolation, none referred to feeling lonely. Indeed, men have been shown to be less lonely than women, and generally describe their friendships in terms of shared activities and practical support (McVilly et al., 2006). These findings have been replicated in this study,

where participants spoke about friendship with peers with whom they played games, had shared community access and enjoyed the same sense of humour. Similarly, the findings of this study support those by Emerson and McVilly (2004) who found that those individuals in supported accommodation had lower levels of friendship activities than those living independently. Perhaps a combination of a lack of opportunity to meet people and absence of choices of people to spend time with while in secure services amplifies this effect.

Parentification refers to children or adolescents assuming adult roles before they are ready (Stein et al., 1999). Because children need their parents, they learn to respond to what their parents need (Chase, 1999). Children may thus assume a parenting role to their own parents or of younger or older siblings, meeting emotional or physical needs (Jurkovic, 1997). An important aspect of this study was the notion that participants spent time emotionally or practically caring for siblings or their parents, or had been parented by their own older siblings.

Parentification has been associated with a range of psychological difficulties including depression, shame, anxiety and social isolation (DiCaccavo, 2006). In a study of the experiences of adolescent children of parents with AIDS, it was found that adult role-taking predicted more emotional distress and problem behaviours such as substance misuse and conduct problems (Stein et al., 1999). Therefore it is possible that the incidences of premature caring in this

study compounded or prompted mental health problems or precipitated rule-breaking behaviours.

Occupational deprivation is a state in which a person or group of people are denied the opportunities to do what is necessary and meaningful in their lives due to outside restrictions (Whiteford, 2000). This could be external circumstances that prevent a person from acquiring, using, or enjoying something (Wilcock, 1998). Wilcock (1998) believes prisoners are most susceptible to occupational deprivation.

It is clear from the results of this study that the restrictions placed on these participants, such as a reliance on staff for outings and activities and a lack of opportunity to develop and pursue their own interests, go beyond the necessary judicial conditions and mental health provisions. It is probable that without the opportunity for meaningful occupation, people develop not only low self efficacy and experience low mood but also develop maladaptive strategies to meet their needs (Ward & Stewart, 2003). This may explain the lengthy detention periods of some of the participants; without occupation they continue to rule-break and are therefore perpetually detained.

Many of the participants had an external locus of control (Rotter, 1954), perhaps due to real restrictions imposed on them throughout their lives. It does appear, however, that the participants in this study readily acknowledged external factors in their own socially unacceptable behaviour and were less able to

acknowledge their own role and responsibility. This can be a natural response to avoid shame and guilt (Tracy & Robins, 2006).

4.3 Methodological Critique

Concerns have been raised about the use of qualitative research as a mode of inquiry with people with ID, in particular in relation to the 'richness' of the data. Smith and Osborn (2003) describe richness as relating to the number of themes that can be identified in sections of the transcript. In a study of self-harm among people with ID in secure services participants talked openly and insightfully (Brown & Beail, 2009). Likewise, in the present study, several themes were identified and participants gave extended, detailed accounts of their experiences. Research with people with ID often trails the equivalent with people in mainstream clinical populations; only recently has this group been given an opportunity to find their "research voice", and it has been shown that people with ID can give useful feedback on their own experiences (Wood et al., 2008).

The generally accepted indicator for a diagnosis of ID is an IQ below 70, as measured by an appropriate and valid scale (WHO, ICD-10, 2001). Common to other forensic studies in services for people who have ID (Crossland et al., 2005, Taylor et al., 2005) there were 3 participants with IQ scores above 70 in the present study. The highest was 75, which falls at the upper level of the confidence limit for diagnosis of ID (AAMR, 2002).

The potential influence of the context in which these interviews took place on participants must be acknowledged. This group of people were living in a highly structured environment and had been receiving services for some time. It may be that past interventions or their residence in an environment where psychological programmes were part of the culture influenced their own conversations about their experiences of relationships and the meanings they ascribed to their behaviour. This "priming" towards sharing and the opportunities to explore themselves and their experiences in a safe therapeutic environment would almost certainly not be a characteristic of the majority of people with ID living in the community, and therefore such rich, detailed data may not be found if this study was replicated using a community sample, particularly if participants had never accessed psychological services.

The expectations that the participants in this study may have had of the principal investigator as a trainee clinical psychologist may explain their propensity to sharing. Indeed, Carolan (2003) noted that during the transcription of her interviews for her research into the experiences of first-time mothers, she was shocked at how audible her voice was, particularly in the earlier interviews she conducted. She found herself cajoling, encouraging, counselling and advising her participants; she attributed this to her role as a trainee midwife. Perhaps betraying my own clinical interest in the psychodynamic model and my experience of using this type of therapy while on placement, I offered explanations and interpretations. This, through the attention paid to reflexivity and the process of keeping a reflective diary,

changed as the study progressed. I acutely appreciated my status as a novice researcher and my desire to “get it right”.

4.4 Clinical Implications

Given the surprising finding that previously unsatisfactory relationships with people “on the outside” became fulfilling following separation, the therapeutic value of these connections should not be underestimated. This emphasises the importance of facilitating ongoing contact with family and friends once a person has been detained, as these relationships can change for the better and have a positive impact upon the client. This change and realisation may be preceded by self-reflection in therapeutic work offered by the clinical team, and as a result, creating the right contingencies for engagement with this work should be considered a priority for the MDT. Parallel to this, the ill-defined sense of self that the participants of this study possessed highlights the potential importance and value of offering relational psychotherapy such as Cognitive Analytic Therapy (Ryle & Kerr, 2002) or psychodynamic interventions to offenders with ID. This work would not only encourage self-reflection but would also drive a person to evaluate their past, current and future relationship experiences.

It may be that the people that agreed to participate in the study were the ones for whom relationships improved. It must be considered that the purposive self-selecting nature of the sample may reflect a bias in experience; and there may be a group of patients who still endure unsatisfactory and unfulfilling relationships with parents, siblings and partners. As discussed previously, the

nature of the secure environment and exposure to therapeutic input from the MDT alongside the engagement of these particular participants may have influenced their willingness to take part in the present study.

4.5 Future Research

Despite the limitations, the present study has demonstrated the value of research that focuses on relationships among people with ID, as has previous qualitative research (Knox & Hickson, 2001). Future research may consider exploring the experience of bullying, both from the viewpoint as a victim and a perpetrator. Bullying is common in secure hospital settings (Ireland, 2004) and impacts not only upon the psychological wellbeing of the target – and possibly also the person responsible – but has a knock-on effect on the atmosphere on the ward and nursing staff.

Little is known about parentification in ID populations. It would be interesting to explore whether ID could be considered a protective or risk factor; perhaps in ID there is an acceptance of situations due to a lack of agency or an absence of knowledge that life could be different which would perhaps result in less mourning for their own “lost” life which has been consumed by caring for others. Likewise, the purpose that caring provides may compensate for the stigma of a diagnosis of ID and the resulting lack of opportunities to be valued by society. However, it is perhaps more likely that as parentification is damaging due to a lack of emotional and practical readiness, ID could be considered a risk factor due to the existence of fewer cognitive and social resources.

Perhaps the priority for future research is further attention to the uncertain sense of self based on the views and reactions of others. It would be interesting to see if this phenomenon was found in non-ID mentally disordered offenders, or in mainstream offenders without comorbid mental health problems.

5 Conclusion

Three superordinate themes emerged in the analysis. These were ‘interpersonal factors’, which explores the way in which relationships begin, progress and end; ‘the internal-external interface’ which is concerned with the interaction between aspects in and of the participants and their environment; and ‘safety’, referring to the actions used to keep participants and others safe.

All participants had experienced damaging relational processes and negative responses from wider society, including in care and education systems as children and the criminal justice and mental health systems as adults. In spite of these experiences, there were also positive relationships and a sense of hope for the future. Despite the limitations of the study, these findings give an insight into the life experiences of patients in secure settings for people with ID, and offers some clinical implications and areas for future research.

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Appendices

Appendix I: Format

The University Of Sheffield.

Department Of Psychology.
Clinical Psychology Unit.

Doctor of Clinical Psychology (DClin Psy) Programme
Clinical supervision training and NHS research training & consultancy.

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Email: c.harrison@sheffield.ac.uk

8 March 2010

Kelly Rayner
Third year trainee
Clinical Psychology Unit
University of Sheffield

Dear Kelly

I am writing to indicate our approval of the journal(s) you have nominated for publishing work contained in your research thesis.

Literature Review: Journal of Applied Research in Intellectual Disabilities

Research Report: Journal of Applied Research in Intellectual Disabilities

Please ensure that you bind this letter and copies of the relevant Instructions to Authors into an appendix in your thesis.

Yours sincerely

Dr Andrew Thompson
Director of Research Training

Journal guidance for authors

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Top

Author Guidelines

1. GENERAL

The *Journal of Applied Research in Intellectual Disabilities* is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

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2. ETHICAL GUIDELINES

The *Journal of Applied Research in Intellectual Disabilities* adheres to the below ethical guidelines for publication and research.

2.1 Authorship and Acknowledgements

Authorship: Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the journal. ALL named authors must have made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL authors must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship.

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5. MANUSCRIPT FORMAT AND STRUCTURE

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-Emerson E. (1995) *Challenging Behaviour: Analysis and Intervention in People with Learning Disabilities*. Cambridge University Press, Cambridge.
-McGill P. & Toogood A. (1993) Organising community placements. In: *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services* (Eds E. Emerson, P. McGill & J. Mansell), pp. 232-259. Chapman and Hall, London.
-Qureshi H. & Alborz A. (1992) Epidemiology of challenging behaviour. *Mental Handicap Research* 5, 130-145

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Appendix II: Ethical and Governance Approval

Consent Form

Patient Information Sheet

Our Ref: 2009/165/S

West Yorkshire Mental Health R&D Consortium
Research & Development Department
North Wing, St Mary's House,
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E-mail: john.hilvy@leedspft.nhs.uk
Direct Line: 0113 295 2387
FAX: 0113 2954466

Kelly Rayner
57 Low Road
Balby
Doncaster
DN4 8PW

23 September 2009

Dear Kelly,

RE: A Qualitative Study to Explore Relationship Experiences of Adult Male Offenders with an Intellectual Disability

My thanks for submitting your project for approval, which was reviewed by the Trust recently.

The panel was very interested in the project, and noted the clarity of presentation and its well designed nature. However a number of issues were raised for which a reply is needed before approval can be given. They are as follows:

1. the Participant Information Sheet (PIS) should present further details of the data storage and protection arrangements for the study
2. the consent form should include a clause for the use of anonymised quotes in reporting, if this is what is intended as a means of illustrating issues raised.
3. the Trust has changed the name of PALS, and the new name should be included to avoid confusion.
4. transfer of data is bound be Trust information governance regulations, and the use of encrypted media should be determined and applied when transferring data.
5. the panel noted the number of possible impacts and applications for the findings of this study. It was felt that these could be spelt out more clearly on the PIS to encourage recruitment.

The Consortium members are:

Review of these issues was delegated to the R&D department, so will not have :o await he next meeting of the full panel. I look forward to receiving these amendments and responses to points of information in the near future.

Final, full approval is granted subject to the following conditions:

- Receipt of all outstanding documents as required above.
- Responses to the issues raised above.

If you have any queries during your research please contact us at any time.

I look forward to your reply and to being able to progress your application.

Yours sincerely

John Hiley
Research Governance & Programme Manager

South Yorkshire Research Ethics Committee
1st Floor Vickers Corridor
Northern General Hospital
Herries Road
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Telephone: 0114 226 9153
Facsimile: 0114 256 2469
Email: joan.brown@sth.nhs.uk

04 November 2009

Ms Kelly Rayner
Clinical Psychology Unit
The University of Sheffield
Western Bank
Sheffield
S10 2TN

Dear Ms Rayner

Study Title:	**A Qualitative Study to Explore Relationship Experiences of Adult Male Offenders with an Intellectual Disability.**
REC reference number:	**09/H1310/72**
Protocol number:	**3**

The Research Ethics Committee reviewed the above application at the meeting held on the 29 October 2009. Thank you for attending to discuss the study.

Discussion

You were congratulated on the quality of your application. This was a well written and well presented application both from a study point of view and from the point of view of identifying and addressing all the ethical issues accurately.

It was observed that some of the participants might have to be interviewed more than once and you explained that this came about through the university peer review sub-committee. The Chair of the committee felt that because some of the participants hac cognitive difficulties it may be necessary to have to interview them more than once. You clarified that you were not anticipating having to interview any participant more than once. It was queried how this judgment would be made be and you confirmed that the decision would be made in consultation with your academic supervisor and with the clinical supervisor at each of the sites. The committee accepted this explanation.

It was observed there was a minor issue that needed addressing in the participant information sheet which is detailed below.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, **subject to the conditions specified below.**

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

Other conditions specified by the REC

- **Submit amended Participant Information Sheet (Version 4 with a new date) as follows:**
  - **Include a section under a heading "Who has reviewed this study?" and explain in it that the application had been reviewed and approved by South Yorkshire Ethics Committee**

The REC nominated the Co-ordinator, Mrs Joan Brown to be the point of contact should further clarification be sought by the applicant upon receipt of the decision letter.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Covering Letter		24 August 2009
REC application		04 September 2009
Protocol	3	01 June 2009
Investigator CV		
Participant Information Sheet (Awaiting Version 4)	3	01 June 2009
Participant Consent Form	3	01 June 2006
Referees or other scientific critique report		26 June 2009
Letter from Sponsor/Statement of Indemnity Arrangements		10 July 2008
Semi Structured Interview Schedule	3	01 June 2009

Notes for Transcribers		
Supervisor CV - Professor Beail		

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Professor Nigel Beail declared an interest in this study because he is your academic supervisor and Reverend Joan Ashton also declared an interest as she had once sat on the same MDT committee as you.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standarc Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, includirg:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/H1310/72	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

Miss Jo Abbott
Chair

Enclosures:	List of names and professions of members who were present at the meeting and those who submitted written comments
	"After ethical review – guidance for researchers" SL-AR2
Copy to:	Richard Hudson, The University of Sheffield
	Helen Oldknow, The R&D Administrator, Research Office, Department of Clinical Effectiveness, Rotherham, Doncaster & South Humber NHS Trust, St Catherine's Hospital, Tickhill Road, Doncaster, DN4 7QN

South Yorkshire Research Ethics Committee

Attendance at Committee meeting on 29 October 2009

Committee Members:

Name	*Profession*	*Present*	*Notes*
Miss Jo Abbott	Consultant in Public Health	Yes	
Dr A H Abdelhafiz	Consultant Physician, Elderly Medicine	Yes	
Reverend Joan Ashton	Co-ordinator of Chaplaincy Services	Yes	
Miss Helen Barlow	Knowledge Service Manager	No	
Professor Nigel Beail	Consultant Clinical Psychologist & Professor of Psychology	Yes	
Mr Ian Cawthorne	Chief Pharmacist	Yes	
Ms Susan Hampshaw	New Deal for Communities Evaluation Unit Manager	Yes	
Professor Nigel King	Professor in Applied Psychology	Yes	
Dr Peter Macfarlane	Consultant Paediatrician	Yes	
Mr Neil Marsden	Police Communications Officer	Yes	
Dr Anton Mayer	Consultant in Paediatric Intensive Care	Yes	
Mrs Andrea Porritt	District Nurse/Practice Educator	Yes	
Dr Ganesh Rao	Consultant Clinical Neurophysiologist	Yes	
Mr Jaydip Ray	Consultant ENT Surgeon	No	
Ms Stephanie Rhodes	Neonatal Sister	No	
Dr Salil R Sen	General Practitioner	Yes	
Dr Paul Spencer	Consultant Radiologist	Yes	
Dr Jonathan Train	Consultant Anaesthetist	No	

Also in attendance:

Name	*Position (or reason for attending)*
Joan Brown	REC Co-ordinator

National Research Ethics Service

South Yorkshire Research Ethics Committee

1st Floor Vickers Corridor
Northern General Hospital
Herries Road
Sheffield
S5 7AU

Tel: 0114 226 9153
Fax: 0114 256 2469
Email: joan.brown@sth.nhs.uk

17 November 2009

Ms Kelly Rayner
Clinical Psychology Unit
The University of Sheffield
Western Bank, Sheffield
S10 2TN

Dear Ms Rayner

Study title:	**A Qualitative Study to Explore Relationship Experiences of Adult Male Offenders with an Intellectual Disability.**
REC reference:	**09/H1310/72**
Protocol number:	**3**
Amendment number:	**1**
Amendment date:	**11 November 2009**

Thank you for your letter of 11 November 2009, notifying the Committee of the above amendment.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

Documents received

The documents received were as follows:

Document	Version	Date
Participant Consent Form	4	11 November 2009
Participant Information Sheet	4	11 November 2009
Notification of a Minor Amendment	1	11 November 2009
Covering Letter		11 November 2009

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

09/H1310/72:	Please quote this number on all correspondence

Yours sincerely

Joan Brown

Mrs Joan Brown
Committee Co-ordinator

Copy to: Lauren Smaller, University of Sheffield

Helen Oldknow, The R&D Administrator, Research Office, Department of Clinical Effectiveness, Rotherham, Doncaster & South Humber NHS Trust, St Catherine's Hospital, Tickhill Road, Doncaster, DN4 7QN

National Research Ethics Service
South Yorkshire Research Ethics Committee
1st Floor Vickers Corridor
Northern General Hospital
Herries Road
Sheffield
S5 7AU

Telephone: 0114 226 9153
Facsimile: 0114 256 2469
Email: joan.brown@sth.nhs.uk

17 November 2009

Ms Kelly Rayner
Clinical Psychology Unit
The University of Sheffield
Western Bank
Sheffield
S10 2TN

Dear Ms Rayner

Full title of study: **A Qualitative Study to Explore Relationship Experiences of Adult Male Offenders with an Intellectual Disability.**

REC reference number: **09/H1310/72**

Protocol number: **3**

Thank you for your letter of 11 November 2009. I can confirm the REC has received the documents listed below as evidence of compliance with the approval conditions detailed in our letter dated 29 October 2009. 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		11 November 2009
Participant Information Sheet	3.1	11 November 2009

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.

09/H1310/72 **Please quote this number on all correspondence**

Yours sincerely

Joan Brown

Mrs Joan Brown
Committee Co-ordinator

Copy to: Lauren Smaller, University of Sheffield

Helen Oldknow, The R&D Administrator, Research Office, Department of Clinical Effectiveness, Rotherham, Doncaster & South Humber NHS Trust, St Catherine's Hospital, Tickhill Road, Doncaster, DN4 7QN

Rotherham Doncaster and South Humber Mental Health NHS
NHS Foundation Trust
Clinical Effectiveness Department
Birch View, St Catherine's Tickhill Road,
Balby, Doncaster. DN4 8QN
Telephone: 01302 796726
Fax: 01302 796729
E.mail : helen.oldknow@rcash.nhs.uk

HJO/CAE

7th December 2009

Ms Kelly Raynor
Trainee Psychologist
Clinical Psychology Unit
Western Bank
Sheffield
S10 2TN

Title of project: **A qualitative study to explore relationships experiences of adult male offenders with an intellectual disability.**

REC reference number: **09/H1310/72**

Dear Ms Raynor

Rotherham Doncaster & South Humber Mental Health NHS Foundation Trust has reviewed your above project for Organisational approval. We can confirm that the research project meets the requirements for Research Governance and we now give you Trust approval.

However if the protocol should change you would have to re-submit your new proposal. May we remind you that you are obliged to adhere to the Research Governance Framework for Health and Social Care.

In the interest of ensuring the Trust receives maximum benefit from co-operating with research projects such as your own, the Trust places great importance on disseminating findings and conclusions. Therefore we would welcome a short summary of the findings of this project, once completed, along with any formal publications resulting from this work.

May I take this opportunity to wish you well with your project. If you have any concerns please do not hesitate to contact Helen Oldknow on 01302 796762.

Yours sincerely

pp Helen Oldknow

Dr Riadh Abed
Medical Director

Our Ref: 2009/165/S

West Yorkshire Mental Health R&D Consortium
Research & Development Department
North Wing, St Mary's House,
St Mary's Road
Leeds LS7 3JX

E-mail: john.hiley@leedspft.nhs.uk
Direct Line: 0113 295 2387
FAX: 0113 2952412

Kelly Rayner
57 Low Road
Balby
Doncaster
DN4 8PW

30 December 2009

Dear Kelly,

RE: A Qualitative Study to Explore Relationship Experiences of Adult Male Offenders with an Intellectual Disability.

Following the recent review of the above project I am pleased to inform you that the above project complies with Research Governance standards, and has been approved by the relevant Consortium Trust management. We now have all the relevant documentation relating to the above project. As such your project may now begin within the South West Yorkshire Partnership NHS Foundation Trust.

This approval is granted subject to the following conditions:

- You must comply with the terms of your ethical approval. Failure to do this will lead to permission to carry out this project being withdrawn. If you make any substantive changes to your protocol you must inform the relevant ethics committee and us immediately.
- You must comply with the Consortium's policy on project monitoring and audit.
- You must comply with the guidelines laid out in the Research Governance Framework for Health and Social Care[1] (RGF). Failure to do this could lead to permission to carry out this research being withdrawn.
- You must comply with any other relevant guidelines including the Data Protection Act, The Health and Safety Act and local Trust Policies and Guidelines.
- If you encounter any problems during your research you must inform your Sponsor and us immediately to seek appropriate advice or assistance.
- Research projects will be added to any formal Department of Health research register.

[1] Details from:
http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4108962&chk=Wde1Tv

The Consortium members are:

- Bradford District Care Trust
- Leeds Partnerships Foundation Trust
- South West Yorkshire Partnerships Trust
- Leeds Metropolitan University
- University of Bradford
- University of Huddersfield
- University of Leeds

Please note that suspected misconduct or fraud should be reported, in the first instance, to local Counter Fraud Specialists for your Trust. Consortium R&D staff are also mandated to do this in line with requirements of the RGF.

Adverse incidents relating to the research procedures and/or SUSARs (suspected unexpected serious adverse reactions) should be reported using **Trust incident reporting procedures in the first instance and to the chief investigator**[2].
They should **also** be reported to:

- The Consortium R&D Department
- the Research Ethics Committee that gave approval for the study
- other related regulatory bodies as appropriate.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

Changes to the agreed protocol MUST be approved by both the Trust/s and Research ethics Committee granting initial approval, before any changes in protocol can be implemented. Copies of revised documents must be provided to the R&D Office. Advice on how to undertake this process can be obtained from R&D.

Projects sponsored by organisations other than the Consortium Trusts are reminded of those organisations obligations as defined in the Research Governance Framework, and the requirements to inform all organisations of any non-compliance with that framework or other relevant regulations discovered during the course of the research project.

Once you have finished your research you will be required to complete a Project Outcome form. This will be sent to you nearer the end date of your project (Please inform us if the expected end date of your project changes for any reason).

We will require a copy of your final report/peer reviewed papers or any other publications relating to this research. Finally we may also request that you provide us with written information relating to your work for dissemination to a variety of audiences including service users and carers, members of staff and members of the general public. You must provide this information on request.

If you have any queries during your research please contact us at any time. May I take this opportunity to wish you well with the project.

Yours sincerely

John Hiley
Research Governance & Programme Manager

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[2] SUSARS – this must be within 24 hours of the discovery of the SUSAR incident

The Consortium members are:

- Bradford District Care Trust
- Leeds Partnerships Foundation Trust
- South West Yorkshire Partnerships Trust
- Leeds Metropolitan University
- University of Bradford
- University of Huddersfield
- University of Leeds

Participant Consent Form.

Title of Project: A qualitative study to explore early relationships of adult males with an intellectual disability in secure settings.

Name of Researcher: **Kelly Rayner**

Please initial box

1. I have read and understand the information sheet for this study. I have had the chance to think about the information and ask questions, and these have been answered. ☐

2. I understand that I do not have to take part. If I say yes now, I can change my mind at any time. ☐

3. I understand that my records will be looked at, and I give permission for this. ☐

4. I agree to my psychologist and nursing team being told that I am taking part in this study.

5. I agree to the interview being tape recorded.

6. I understand that relevant sections of any of my medical notes and data collected during the study may be looked at by individuals from the Research Support Office in the Clinical Psychology Unit, or by regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records

7. I agree to take part in the study.

Name of Patient	Date	Signature
Name of Person taking consent	Date	Signature

Participant Consent Form.

Title of Project: A qualitative study to explore early relationships of adult males with an intellectual disability in secure settings.

Name of Researcher: **Kelly Rayner**

Please initial box

1. I have read and understand the information sheet for this study. I have had the chance to think about the information and ask questions, and these have been answered. ☐

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Name of Patient	Date	Signature
Name of Person taking consent	Date	Signature

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Title of Project: A qualitative study to explore early relationships of adult males with an intellectual disability in secure settings.

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what you will be asked to do. Please read this information carefully and talk about it with other people if you want to. Ask us if there is anything that you don't understand. Take time to decide whether or not you want to take part.

Do I have to take part?

It is up to you to decide. We will describe the study and go through this information sheet, which we will then give to you. We will then ask you to sign a consent form to show you have agreed to take part.

Can I change my mind?

Yes, of course. You can change your mind at any time, even during the interview. You just need to tell us. We will not mind.

What is the purpose of the study?

We are doing a project on people's experiences of relationships. We want to talk to you about how life was growing up, and about people in your family and friends. We need your help to find this out as we are interested in what YOU think. We will also want to talk to someone who has worked with you to ask them a bit about you before we talk to you.

Who is doing the study?

The project is being done by Kelly Rayner from Sheffield University as part of an educational qualification. Kelly will be the person who speaks to you if you decide you want to take part.

The University Of Sheffield.

What do I have to do?

We would like to meet with you for about an hour to talk about your experiences of family and friends. This talk will take place at the place where you usually go to see your psychologist.

When and where will the interviews take place?

The interview sessions will be held in the room you normally see your psychologist, at a time to suit you.

What other information will be collected in the study?

With your agreement, we will also obtain information from your files.

Why should I take part?

You are the most important person at your psychology meetings so it is important for us to find out what you think. This is a chance for you to have your say: we will listen to you. You can help us to find out how things have been for you by telling us what was good and bad about growing up and ways in which people could help people like you.

This will help to make services better for all people with learning disabilities who go to them. It could help make services better for children and their families and it could help make services for adults better, including Amber Lodge.

Will you tell anyone what I say?

We might write down what you say and would like to tape record the whole interview so that we don't forget what you say. BUT we will not let other people listen to your tape, see what we've written or tell them what you've said.

No one except the researchers will know your name or where you live. The only time we would tell anyone what you said was if you told us you or someone else was in danger. We will need to talk to someone from your staff team if this happens, but we would speak to you about it first.

Will anyone else be told about my participation in the study?

We will let your psychologist and ward staff team know that you are taking part BUT we won't tell any of them what you have said. The only time we would tell anyone what you said was if you told us you or someone else was in danger. We will need to talk to your team if this happens, but we would speak to you about it first.

What happens afterwards?

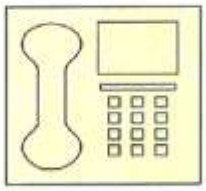
We will write a report about what all the people who have talked to us have said, but we will not use your name (or anyone else's!). No-one will know who said what. The report will help to work out what could be done to help people like you who see a psychologist, and who are in secure services. If you would like to read the report you can ask your psychologist and they will give you a copy to keep. All the information about the project will be kept in a locked cabinet, and nobody except Kelly and Alan will be able to read any computer files (they will be encrypted). This information will be kept for 5 years.

Can I talk to you first?

Yes, of course. We would be very happy to talk to you.

Ring 0114 2226650 and ask to leave a message for Kelly Rayner with your name and where you live. Kelly will then phone you back as soon as possible.

Or you can ask to speak to your psychologist.



What if I am not happy and want to complain?

If you have any complaints or concerns please contact the project co-ordinator: (Professor Nigel Beail, 01226 777785) Otherwise you can use the normal University complaints procedure and contact the following person: Dr David Fletcher, Registrar and Secretary's Office, University of Sheffield, Firth Court, Western Bank, Sheffield S10 2TN. You could also speak to your psychologist or ring 0114 2226650 and leave a message for Kelly Rayner. PALS are also available to speak to. You can contact them on 0800 0154334.

The University Of Sheffield.

PALS
Patient Advice and Liaison Service

Who has reviewed this study?

This research project has been reviewed and approved by South Yorkshire Ethics Committee.

Participant Information Sheet.

Title of Project: A qualitative study to explore early relationships of adult males with an intellectual disability in secure settings.

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what you will be asked to do. Please read this information carefully and talk about it with other people if you want to. Ask us if there is anything that you don't understand. Take time to decide whether or not you want to take part.

Do I have to take part?

It is up to you to decide. We will describe the study and go through this information sheet, which we will then give to you. We will then ask you to sign a consent form to show you have agreed to take part.

Can I change my mind?

Yes, of course. You can change your mind at any time, even during the interview. You just need to tell us. We will not mind.

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The University Of Sheffield.

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This will help to make services better for all people with learning disabilities who go to them. It could help make services better for children and their families and it could help make services for adults better, including Newton Lodge.

Will you tell anyone what I say?

We might write down what you say and would like to tape record the whole interview so that we don't forget what you say. BUT we will not let other people listen to your tape, see what we've written or tell them what you've said.

No one except the researchers will know your name or where you live. The only time we would tell anyone what you said was if you told us you or someone else was in danger. We will need to talk to someone from your staff team if this happens, but we would speak to you about it first.

Will anyone else be told about my participation in the study?

We will let your psychologist and ward staff team know that you are taking part BUT we won't tell any of them what you have said. The only time we would tell anyone what you said was if you told us you or someone else was in danger. We will need to talk to your team if this happens, but we would speak to you about it first.

What happens afterwards?

We will write a report about what all the people who have talked to us have said, but we will not use your name (or anyone else's!). No-one will know who said what. The report will help to work out what could be done to help people like you who see a psychologist, and who are in secure services. If you would like to read the report you can ask your psychologist and they will give you a copy to keep. All the information about the project will be kept in a locked cabinet, and nobody except Kelly and Harry will be able to read any computer files (they will be encrypted). This information will be kept for 5 years.

Can I talk to you first?

Yes, of course. We would be very happy to talk to you.

Ring 0114 2226650 and ask to leave a message for Kelly Rayner with your name and where you live. Kelly will then phone you back as soon as possible.

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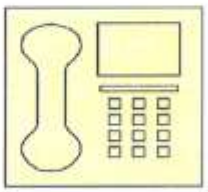

What if I am not happy and want to complain?

If you have any complaints or concerns please contact the project co-ordinator: (Professor Nigel Beail, 01226 777785) Otherwise you can use the normal University complaints procedure and contact the following person: Dr David Fletcher, Registrar and Secretary's Office, University of Sheffield, Firth Court, Western Bank, Sheffield S10 2TN. You could also speak to your psychologist or ring 0114 2226650 and leave a message for Kelly Rayner. South West Yorkshire NHS Trust Customer Service Department are also available to speak to. You can contact them on 0800 5872108.

The University Of Sheffield.

Who has reviewed this study?

This research project has been reviewed and approved by South Yorkshire Ethics Committee.

Appendix III: Interview Schedule

Analysis Exemplar

Interview Schedule

After brief orientation to the interview outlining purpose, confidentiality, length, breaks etc the following questions will be used as a guideline to ask participants. The interview will be led by the participant as much as possible.

Describing themselves

1. How would you describe yourself as a person

   Prompt: physical traits? Personality? Behaviour?

2. What kinds of things do you like doing?

   Prompt: Activities, hobbies?

Family life

Q. Can you tell me about your family?

Prompts might include:

- How would you describe growing up/ your family life, who is in the family?
- What was it like growing up?
- Where did you grow up or live growing up? What was that like for you?

Q. Can you tell me about your relationship with [insert family member]? (if not already described)

Prompts:

- Relationship with each parent, grandparent, sibling and significant others already mentioned.
- Was there any conflict within the family? What happened? How did it affect you?

Q. Have you had any other important relationships?

Prompts:

- Friends
- Other relatives
- Girlfriends / Boyfriends
- Junior / Secondary School / Special School / College
- Since left school

Final Questions

Is there anything else you would like to add to your experiences?

Close the interview with:

Checking how the person is feeling and if they would like to arrange some more 1:1 support within their psychology provision to discuss any feelings/ difficulties arising from the interview.

Analysis Exemplar

The following details the analysis process as detailed in the methodology section. The example is taken from Nick.

Making preliminary notes

Initially the transcript was read several times for the principal investigator to become familiar with the content. Each interview transcript was read and coded in turn in the left margin including initial noting, descriptive, linguistic and conceptual comments as well as initial interpretations.

Principal investigator's initial notes	Interview text
Not seen his sister for over 10 years. Confused account of timeline/age difference. His sister was taken into care but he wasn't. Seems to be talking almost to self – commentary. Difficulty expressing self coherently. Sister's behaviours impacting upon his niece – she is at fault. Uncertain of current status of sister.	**Nick:** But my sister, I haven't seen her for…at least 10 years ago…erm…actually, when I was about 20 my sister, I think I was 20, was I 20? No, I think I was about 17, my sister got placed into care into a children's home in XXXX. And when my mum was alive, she and my dad as well would see her, but since she left care, she's…I haven't seen her to find out, but last time I saw her, she was like on drugs, and was dealing drugs and taking drugs and everything. And I know my niece, well she's a lot older now, when my niece was about 12 years old, she ended up in care as well because of what my sister was doing.
	Researcher: Yeah.
What did he infer from my "yeah"? Not seen brother for over 10 years. Swings from certainty ("know") to uncertainty ("maybe"). Problems remembering. Timeline not important?	**Nick:** I know. And my brother, I haven't seen him for at least 10 years, maybe 12 years. Erm…
	Researcher: Before you were in prison then? Last time you saw your brother?
Uncertainty. Trying to help me understand. Blames recall problems on passage of time. Brother has changed for the worse. Good vs bad. Where does he see himself? Relying on information from his father. Mum set up financial supports for his brother.	**Nick:** Yeah. I don't know, it just seems that long ago, you know. And last time I saw my brother he was a good kid, but now only through hearing about it, like my dad told me or…Before my mum died she left, she set up a trust fund for my brother for when he was 18.
	Researcher: Are you the oldest child then?
Sister oldest sibling. Uncertain how old she is. Takes subject back to his younger brother. Seems preoccupied with what he did to his family. Motivated by money, and chose that over family life. Dad decided not to have a relationship with his brother as a result. Brother is homosexual, "found out" – heard from someone else? Nick is happy to respect this aspect of his brother. Emphasises that he has no problems with homo- or bi-sexual people. Stresses that he is heterosexual – seems important to him to emphasise this.	**Nick:** No, my sister is. My sister's in her 30s now. I'm not actually sure how old she is. But my mother set up this trust fund like family for when he's 18. He left home at 16, and as soon as he got hold of the money, he didn't want to know his family. So, my dad says to me, "he'll come back when he's run out of money" but he said he wouldn't have nowt to do with him. I found out my brother's gay as well but if that's what he wants I'm happy for him. You know? I'm not against people who are either bisexual or gay or whatever as long as they don't try owt with me, you know. If that don't happen then I'm not...it don't matter, I've had gay friends before, they've never tried owt you know. So, as far as that goes its fine.

Noting preliminary subordinate themes

The preliminary notes were then summarised in order to identify emerging themes. These were noted in the right hand margin.

Interview text	Emerging Themes
Nick: But my sister, I haven't seen her for…at least 10 years ago…erm…actually, when I was about 20 my sister, I think I was 20, was I 20? No, I think I was about 17, my sister got placed into care into a children's home in XXXX. And when my mum was alive, she and my dad as well would see her, but since she left care, she's…I haven't seen her to find out, but last time I saw her, she was like on drugs, and was dealing drugs and taking drugs and everything. And I know my niece, well she's a lot older now, when my niece was about 12 years old, she ended up in care as well because of what my sister was doing.	Rupture – lack of contact with sister. Confused timeline – lack of recall. Relying on others for information. Care system. Consequences of behaviour.
Researcher: Yeah.	
Nick: I know. And my brother, I haven't seen him for at least 10 years, maybe 12 years. Erm…	Rupture – lack of contact with brother.
Researcher: Before you were in prison then? Last time you saw your brother?	
Nick: Yeah. I don't know, it just seems that long ago, you know. And last time I saw my brother he was a good kid, but now only through hearing about it, like my dad told me or…Before my mum died she left, she set up a trust fund for my brother for when he was 18.	Confused timeline – lack of recall. Relying on others for information.
Researcher: Are you the oldest child then?	
Nick: No, my sister is. My sister's in her 30s now. I'm not actually sure how old she is. But my mother set up this trust fund like family for when he's 18. He left home at 16, and as soon as he got hold of the money, he didn't want to know his family. So, my dad says to me, "he'll come back when he's run out of money" but he said he wouldn't have nowt to do with him. I found out my brother's gay as well but if that's what he wants I'm happy for him. You know? I'm not against people who are either bisexual or gay or whatever as long as they don't try owt with me, you know. If that don't happen then I'm not...it don't matter, I've had gay friends before, they've never tried owt you know. So, as far as that goes its fine.	Rupture. Rejection. Consequences of behaviour. Identity.

When the entire transcript had been analysed this way, the emergent themes were listed. For Nick, the preliminary emergent themes were:

- Treatment as a means of self-improvement
- Treatment as a means to move on
- Being rescued
- Staff support
- Being cared for
- Blame
- Punishment
- Discipline
- Consequence
- Abuse
- Exploitation
- Others making decisions
- Making own decisions
- Reliance on others for information
- Reliance on self
- Arguments with parents
- Arguments with siblings
- Loss of contact/estrangement
- Rejection
- Growth/repair in relationships
- Stability of behaviour
- Stability of family contact
- Stability of placement
- Transiency of romantic relationships
- Lack of recall
- Identity of self
- Identity/perception of family members
- Change in role
- Activities

The locations of the themes were noted by making a note of the line number from which it originated in the transcript.

Grouping subordinate themes and forming a master table

The emergent themes were then grouped together in clusters, with examples of raw data illustrating each theme linked to the transcript and line numbers in order to create a set of superordinate and subordinate themes.

Superordinate theme	Subordinate theme	Emergent notes	Quote	Line
Treatment	Treatment as a means of self-improvement	Treatment – means to self-improve and progress. Achievement. Fulfilling expectations.	Shopping for yourself. Err, I think about 8 months ago I was in a session for cooking and that went well. I did it for so many weeks. I do cooking for life as well, which is all about food and hygiene. Basically the plan is for me to pass my food and hygiene, I already passed it once, but this is like four or five years ago.	55-59.
Treatment	Treatment as a means of self-improvement	Recognition that people can change. Importance of maturing and developing. Difficult to describe.	But now when I go home my dad and my stepmum are just two different people all together from then. And I am as well, obviously 'cause I grew up and you know, and I, err…	111-113.
Treatment	Treatment as a means to impress/move on.	Treatment – engagement as a means to impress staff.	But I'm gonna still do it, I tend to do all my sessions, cause it goes good for you in the long run.	44-45.
Others as protectors.	Staff support	Support from staff – satisfied.	And since I've been here I'm satisfied with the support and treatment you know.	84-85.
Others as protectors.	Cared for	Parented by older sister. Unsure of her age, lack of recall or closeness now.	Well when I were a kid it were my sister who looked after me. Yeah she I think she I'm only having a rough guess I think she'd be in her thirties now. Bout 36, 37, she might be a bit younger than that but I don't know.	202-204.
Punishment, discipline, consequences.	Bad behaviour.	School not a problem for Nick – although he caused them for others. Loose, vague description of discipline.	Like teenagers, they get a bit feisty you know with the teachers, so I shouted and swore at teachers but you know then my dad like got a letter "oh your son's being a bit disruptive" and my dad says "oh chill out you" yeah.	172-175.
Punishment, discipline, consequences.	Lack of consequence.	Knowledge of the law. Boundary pushing with few consequences. Minimising troublemaking.	I were just like picking bottles up and smashing windows and kicking bins over. They didn't charge me with anything cause they couldn't really, you know.	178-179.
Dependence	Others making decisions.	Waiting – reliance on others to make decisions.	I didn't think it would ever come. You know, time just seemed to be passing and just wouldn't stop. And I thought I wonder when's it all gonna come and be good news for me.	23-25.
Dependence	Relying on others for information.	Responsibility of school to keep kids there, not parents to discipline and set boundaries? Vague notion of bad behaviour – relying on others for knowledge.	Yeah it's because she was she was like missing school and stuff you know and truanting all the time. And the school what she was at couldn't keep her in you know. Well that's what I got told anyway.	163-165.

Superordinate theme	Subordinate theme	Emergent notes	Quote	Line
Rupture.	Argument with parents.	Normalising experiences of arguing with parents. Differing perceptions of "wrong" and "right".	Suppose it's like every teenager or late teenagers, you argue with your mums, you argue with your dads like. I argued with my mum when she were drunk I said "mum, you're drinking too much", leave me alone, you know. I'm enjoying my...I'm not doing anything wrong. You know.	188-191.
Rupture	Arguments with sister.	Used to argue with sister, minimising now with hindsight.	But yeah, like as far as getting on with my sister, when we lived together the whole family me and my sister was always arguing, you know about little things, you know.	204-206.
Repair.	Working on relationships.	Too soon? Recognition that relationships not always easy and need work and persistence. Collaboration.	Erm, so then my dad, shortly after my dad met me stepmother and eventually, it took a while but eventually we started getting on with each other.	108-110.
Stability	Of behaviour.	Being settled and calm – no function of being agitated.	I've never kicked off, you know. Basically cause I don't see no point in it.	6-7.
Stability	Of family contact.	Regular visits "home". Family contact.	I go home to see my dad and my step-mum once a month.	76.
Instability	Transiency of romantic relationships.	Difference between "good" and "bad relationships – people and experiences are either good or bad. Failure to succeed at a good relationship. Fails to "keep" people interested/committed.	I've had err I've had partners. Err but it turns out that I see err...when I get the bad ones, I can keep hold of them, but when I get hold of the good 'uns I can't.	234-235.
Instability	Change in role compared to friends.	Friends moved away – change of role. Different to Nick.	All my friends don't live there no more, they've all got married and become mothers or fathers so.	82-84.
Lack of recall		Lack of recall. Confused memories.	But erm, I can't really remember what age I was. I can see myself but I can't place an age.	161-162.
Lack of recall		Lack of recall/willingness to share details about childhood. Awareness and acknowledging that he could be confusing his own memories with those mentioned by others.	I can't really remember owt about it really. I have like a picture in my head 'cause I've seen photos of me when I were a baby. And I've seen other photos of family, but that's only as far as I can remember.	224-226.

Superordinate theme	Subordinate theme	Emergent notes	Quote	Line
Identity of family members	Mum	Trying to understand Mum as an alcoholic. Pre-emptive defending of his Mum from negative perceptions of others.	But she were just like, in my eyes you get two types two types of alcoholics. You get one type of alcoholic that are drinking and they do nothing, just louch around. But you can get other type of alcoholics where they erm, she like, my mum were an alcoholic and she were drinking but she were going round, she had a job, she were cleaning the old peoples' homes, well like bungalows. She were cleaning them, and then she were coming home and doing normal things you know.	191-197.
Identity of family members	Mum	Mum's alcoholism caused her death. "Proper" as opposed to stepmum. Matter of fact but stuttering and repetitive. Difficult to talk about. Self-blame? He wasn't there to save her.	Err, my proper mum, well she died in 1993 in a house fire. Erm, basically what had happened was I was in hospital at the time, and it was a week before Christmas, and basically what had happened was she had been drinking, because she was an alcoholic, and she laid on the settee with a cigarette in her hand, and the cigarette went on the settee and caught fire and she burnt to death.	103-108.
Identity of family members	Dad	Trying to understand Dad as an alcoholic. Pre-emptive defending of his Dad from negative perceptions of others.	No. No, well he does drink, but not like he did. He just. He never drinks during the week 'cause he works. But maybe on a Friday he might have a couple of cans. On a Saturday during the day he might have a couple but…	116-118.
Identity of family members	Brother	Trying to understand his brother's identity as homosexual. Seems to be making it clear he has no issue with people being gay but also emphasises strongly his sexuality.	I found out my brother's gay as well but if that's what he wants I'm happy for him. You know? I'm not against people who are either bisexual or gay or whatever as long as they don't try owt with me, you know. If that don't happen then I'm not...it don't matter, I've had gay friends before, they've never tried owt you know. So, as far as that goes its fine.	149-154.
Identity of family members	Brother	Brother a "good boy" as never been to prison. Also never taken into care so not separated from his family as a child.	He's the only one who's not been in prison he's not been in care he's not/as far as I can remember he's never been in trouble with the police either.	159-161.
Exploitation.	Partners.	Partners taking advantage. Trying to be a "good" man/partner, and being used by women. Happened with more than one woman. Exploitation.	I was always like going out you know trying to earn some money and I'd come back and they'd say "oh, can you lend me this" and that.	241-243.
Activities.	Mix.	Activities – eclectic mix; open mind.	Erm, and to keep myself occupied I just listen to music, watch telly, I've got quite a few DVDs, a different mixture. Erm, covers a wide range of things really.	61-63.

This process was repeated for all seven transcripts, producing a master table for each. The master lists were then examined to establish superordinate themes. This process included identifying some themes that were not sufficiently common to all participants which were then not pursued for the remainder of the analysis. A decision was also made regarding which themes were important even if they did not appear in every transcript. This provided a conceptual model of participants' experiences with verbatim extracts of raw data used as illustration to ensure that themes were grounded in the data.