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Narratives around sex and relationships in forensic and community

Intellectual Disability services

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Introductory chapter – thesis overview

Recent developments and challenges in care services for people with intellectual disability (ID) have highlighted the need to transform services. This involves a continuing emphasis on reintegration to society for those receiving support within hospital settings, with a focus on providing person-centred care with the individual at the heart of their support (Transforming Care, 2015).

Coupled with an increasing emphasis on research involving people with ID over the past two decades (Garcia Iriarte, O’Brien & Chadwick, 2014), we are better positioned to understand, and respond to, the needs of people with ID. However, some areas important to service user quality of life (Schalock et al., 2002) remain under-represented. The current thesis will draw together, and extend, the evidence base on one such area: that of individuals’ sexual rights and relationships. The author’s experience and interest in forensic environments has influenced an emphasis on offending behaviour, or behavioural phenomena likely to lead to detention in secure services. This thesis will attempt to provide insight into the status quo within such services, and provide recommendations for improving future practice.

Chapter one comprises a systematic review exploring staff perceptions of sexual offending-type behaviours (SOTB) displayed by people with ID living within community or secure services. Historically, such behaviours have been considered characteristic of the ID, with efforts to explain or address the phenomena only occurring more recently (Haaven, 2009). With the well documented over-representation of individuals with ID in the sex-offender population (Craig & Lindsay, 2010), it is important to consider how staff currently view and respond to SOTB, and the related consequences for the individuals concerned. The systematic review draws together both qualitative and quantitative research, examines themes and differences in the findings, and considers implications for future clinical and research developments.

A note on terminology: the term intellectual disability will be used throughout the thesis, unless other terms have been adopted by participants in their speech. The use of different terminology remains a contentious topic, and services supporting people with ID are often called ‘learning disability’ services. However, to fit with the international understanding of the client population, and the use of specific terminology within the research field (Shalock et al., 2007), ‘intellectual disability’ will be used throughout.
Chapter two, the empirical paper, builds on the findings of chapter one, particularly in reference to the terminology staff use to construct, and respond to, SOTB. Using a qualitative methodology, the researcher explores service users’ interactions with staff related to sex and relationships, within a secure hospital for people with ID. Using critical discourse analysis (van Dijk, 2008), interviews are analysed to consider the prevalent discourses within the hospital setting, and the function of these in precipitating or maintaining inequality and power imbalances. Implications for ensuring that service users’ relationship rights are upheld, and reflections on the culture surrounding development of social and sexual identity in ID services, are discussed.

Finally, a chapter of appendices provides supplementary material to elaborate on the processes described in chapters one and two.

References


Chapter one – Literature review

Exploring staff perceptions of sexual offending type behaviours (SOTBs) perpetrated by service
users with intellectual disability (ID): A systematic review.

Nici Grace, Trainee Clinical Psychologist, University of Liverpool
Abstract

Background

Sexual offending-type behaviours (SOTB) are commonplace within both community, and secure, services for individuals with intellectual disability (ID). Such behaviours are often unreported, and appropriate interventions to reduce likelihood of reoccurrence are thus inaccessible. The current systematic review synthesises the existing literature surrounding staff perceptions of SOTB, and considers factors influencing reporting of SOTB, alongside implications for services and their users.

Method

The Preferred Reporting Items for Systematic Reviews and Meta-analyses PRISMA guidelines were followed, and six databases were searched according to pre-determined search terms. The researcher, alongside an independent co-reviewer, reviewed potential results for inclusion. The author screened full text copies of articles, undertook quality assessment and extracted relevant data, while the co-reviewer checked extracted information for accuracy.

Results

In total, five quantitative and two qualitative studies were identified. Staff predominantly attributed behaviour as being stable and internal to the individual, however this varied dependent on staff role and proximity to direct care, and perceived severity of behaviour. Emotional responses included anger, disgust and occasionally sympathy, while qualitative reflections highlighted struggles around empathy. Individuals with ID were unlikely to be reported to the police, due to a lack of expected consequences, or a perceived need for help rather than punishment. The context of care (forensic or community) did not appear to influence responses to behaviour.

Conclusions

The implications for pursuing legal or therapeutic avenues to reduce likelihood of recurrence are discussed. The inconsistent response both within, and between, services, is likely to contribute to confusion for SUs around appropriate and legal behaviour. Guidance informing a consistent approach, within the auspices of legal frameworks regarding criminal justice system involvement, is required.
within ID services. Future research directions pertaining to training and the influence of discourse in interaction are considered, in light of the existing literature base and potential improvement of services.

**Key terms:** intellectual disability, sexual/offences, staff, attributions.
Background

Services supporting individuals with intellectual disability

People with ID, by definition, experience higher support needs relative to the general population, particularly in areas related to socio-affective functioning (e.g. Whitehouse, Chamberlain & O’Brien, 2001, Whitaker, 2015). As such, individuals often require support to maintain effective interpersonal relationships, including developing appropriate mechanisms to communicate needs. A wealth of research has explored the difficulties that can occur when communicative tools used to express discomfort or needs can potentially put the safety of the individual or others at risk (Royal College of Psychiatrists [RCPsych] & British Psychological Society [BPS], 2016). Often referred to as ‘challenging behaviour’, this can include acts of aggression and physical or sexual violence, which challenge services’ support, and leaves the individual vulnerable to being subjected to restrictive practices (RCPsych & BPS, 2016). Despite the emphasis on understanding challenging behaviour as a communicative tool, some individuals attract the attention of legal services due to the nature or severity of the behaviour, and the risks this presents to the individual themselves, and to others. This is particularly the case in relation to inappropriate sexual behaviours, with the individual more likely to be referred to long stay secure services (Lindsay et al., 2013).

People with ID who sexually offend

Research has found dramatic variations in the prevalence of individuals with ID in the Criminal Justice System (CJS; Loucks, 2007), often due to methodological difficulties in assessing the level and nature of ID. It is acknowledged, however, that those with ID are over-represented in both mainstream offending and sex-offending populations (Craig & Lindsay, 2010). Further to those identified within the prison system, research indicates that difficulties around sexual offending (SO) or sexually inappropriate behaviour (SIB) are highly prevalent within forensic ID community services, with almost half (45.3%) referrals into such services requiring support to develop more appropriate sexual behaviour (Lindsay et al., 2013). Alongside those progressing down a forensic route, a vast number of individuals do not attract CJS attention: McBrien, Hodgetts and Gregory (2003) found that 41% of individuals in contact with ID health and social care services displayed sex-
related offending or ‘risky’ behaviour, whereas only 9.4% of the overall population was known to the CJS. This is further complicated by the lack of validated risk assessments available for the ID population (Lofthouse et al., 2013), perhaps adding to the difficulty in judging risk associated with behaviours and associated need for intervention.

The reasons for these multiple pathways for individuals with ID who sexually offend are varied. Legally, an individual will be awarded a custodial disposal if they are found to be criminally responsible for an illegal act, known as having ‘mens rea’ (e.g. Nevins-Saunders, 2012). The presence of an ID may indicate that an individual does not hold the necessary cognitive or emotional capacity to fully understand the legal consequences of their actions, or manage their behaviour accordingly (Price-Jones & Barrowcliffe, 2010). In such cases, disposal via community or secure specialist forensic services will be sought. Diversion from the CJS has been strongly recommended, and successfully executed (Durken, Saunders, Gadsby & Hazard, 2014) following the recommendations of Lord Francis’ report into individuals with ID and mental health problems within the CJS (Department of Health, 2009). Pursuing secure detention of individuals with ID has, however, become complicated by the Transforming Care agenda, with service providers mindful of reducing the potential for restrictive practice in locked settings (see Flynn & Citarella, 2012 for a discussion of the Winterbourne scandal and practice implications). As such, formal avenues of diversion to secure settings are rarely followed, and the decision whether to report is often made by other individuals, using alternative reasoning, outside of the formal legal process (McBrien & Murphy, 2006).

Previous research has attempted to investigate variables pertinent to reporting of sexual offences of individuals with ID, and has considered characteristics related to the reporter, victim, offender and offence. However, few consistent findings have emerged. In possibly the most comprehensive study to date, McBrien and Murphy (2006) investigated care staff and police views on whether offences of ID and non-ID offenders should be reported. While consideration of sexual offences was not a major focus of the study, results showed that care staff were significantly less likely than police to believe that a rape perpetrated by an ID service user should be reported. This was due to a perceived need for help and understanding, rather than punishment. The generalisability of
these findings are, however, questionable: the study suggested that police officers chose to report 100% of rape offences, whereas in practice, police responses to individuals with IDs are often inconsistent (Jacobson, 2008).

The type of offence committed has also been found to impact the likelihood of reporting alleged perpetrators with ID. McBrien, Hodgetts and Gregory (2003) stated that sexual offences were more likely to be reported to the police than non-sexual offences, irrespective of the perpetrator’s level of ID. In a study of school environments for young people with IDs, Fyson (2007) found that reporting was often contingent on perceived severity of offence, with behaviours other than penetrative rape often described as “nuisance” rather than offending behaviours. As such, they did not attract police or CJS attention. The study’s focus on schools, however, may indicate that these findings are specific only to younger individuals.

Victim characteristics are also important here: Green, Gray and Willner (2002) found that, even within sex offences, those committed against adult victims were less likely to result in prosecution compared to those with offences against children. Victims with ID, including those deemed to lack the capacity to consent to sexual activity (Mental Capacity Act [MCA], DOH 2005) are thought to experience high rates of sexual abuse victimisation, but very low rates of court proceedings and prosecutions (Peckham, 2007). This may, however, be due to court proceedings being contingent on assessing the victim’s capacity to consent to sexual activity, a notoriously difficult decision (Murphy, 2003).

Characteristics of the offender may also play a role in influencing responses to SO or SIB. Reed, Russel, Xenitidis and Murphy (2004) identified that, were it not for the presence of ID, many individuals would face legal ramifications for behaviour which currently goes un-reported. There has, however, been little research exploring the specific aspects of the ID, or staff perceptions of such, which impact on reporting of alleged offences, and this will be explored in the current review.
The rationale for neglecting to report offences perpetrated by individuals with ID often originates from a wish to protect those considered vulnerable. Fyson (2007) found that teachers were reluctant to report alleged sexual offences committed by adolescents with ID due to fearing the implications of a sex offender ‘label’ on the young person. Despite the protective intent, Fyson identifies that this inadvertently removes the opportunity for intervention, simultaneously increasing the likelihood of further offending. Similarly, O’Callahan (1998) suggests that a lack of appropriate responses to young offenders has negative implications for their later offending trajectory, potentially leading to more persistent offending.

Theories of sexual offending within ID populations are inherently influenced by a lack of learning opportunities with regards to both the theoretical, and practical, aspects of interpersonal and sexual relationships. For example, the Counterfeit Deviance Hypothesis (Griffiths, Hinsburger, Hoath & Ioannou, 2013) suggests that those with ID do not simply have deviant sexual preferences, but lack the requisite skills and knowledge to pursue legal and appropriate sexual relationships. These difficulties are then exacerbated by the restricted opportunities to pursue appropriate romantic or sexual relationships, due to legal frameworks and the nuances inherent in determining capacity to consent to sexual activity (MCA, 2005). Similarly, Ward and Siegert (2002) suggest that emotional and behavioural regulation difficulties cause an inability to inhibit sexual desires which could be deemed ‘inappropriate’, and shape intimacy-seeking behaviour accordingly. In this regard, interventions to reduce the likelihood of reoffending will require both individual and systemic approaches targeting intra- and inter-personal functioning (Craig & Lindsay, 2010).

Despite methodological difficulties in assessing recidivism, and the confounding impact of environmental influences, statistics show a general trend in lower recidivism rates following completion of sex-offender treatment programmes, compared to those not in receipt of treatment (Courtney & Rose, 2004; Rose, Rose, Hawkins & Anderson, 2012). Early intervention in relation to sexually offending behaviour is considered to be an important factor affecting offending outcomes (O’Callahan, 1998). Without reporting sexual offending behaviour, individuals with IDs are unable to
access treatment opportunities, and the risk of reoffending remains high. This further emphasises the need to report offences, and support individuals to progress through the CJS in line with relevant legal frameworks.

Alongside the risk of potential harm to future victims, the rights of the offender must also be considered. In line with the Human Rights Act (HRA, 1998), in instances of alleged criminal offences, the individual’s right to a fair hearing (Article 6) indicates that no assumptions can be made about the commission of an act, without an opportunity for that individual to defend themselves. Without following due legal process these rights may be infringed, and the individuals may subsequently face informal and unmonitored sanctions imposed by staff teams, infringing their right to no punishment without law (Carson, 1989; as cited in McBrien & Murphy, 2006).

Previous reviews and rationale for the current review

Views held by staff supporting individuals with ID are likely to influence the culture within services, in turn impacting on practices that support and monitor service users’ sexual experiences and well-being (Brodwin & Frederick, 2010). Previous research has explored staff attitudes and responses to both sexuality and sexual behaviour. This has, however, often relied on investigating narrow and specific populations, using a variety of methodologies and a range of idiographic measures, often producing results not generalisable to other populations. Studies have provided implications relating to the needs of both service users and staff, to improve support in ID services. However, attempts to follow recommendations from all individual studies would provide overwhelming and unmanageable directions for clinical practice. Given the considerable implications in terms of risk to future victims, and the lack of previous systematic reviews on the subject, it is important to draw together the available literature. This will enable the development of a comprehensive understanding of the factors contingent upon responses to sexual offending, while considering the clinical implications, and identifying gaps in the literature to inform future research directions.
Objectives

The aim of the current review is to examine the published literature regarding staff appraisals of sexual offences committed by service users IDs. More specifically, the review aims to answer the following questions:

1. How do staff view sexual offending type behaviour carried out by service users with ID in their care?

2. What are the factors influencing staff responses to alleged offences, and how will this influence future remediation and recidivism trajectories?

3. What are the implications of the findings for future clinical and research practice?
Search strategy

The methods utilised when undertaking the current systematic review were guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Moher, Liberati, Tetzlaff & Altman, 2009).

Databases

In order to ensure maximum inclusivity of relevant research across a variety of disciplines, the following databases were selected for electronic searching: Scopus, CINAHL PLUS, PsycINFO, British Library EThoS, Science Direct and Medline. Due to the influence of criminal justice legislation, publications available from The Home Office were also searched, but yielded no results. Hand searching the reference lists of articles selected for inclusion in the review, enabled identification of other relevant articles.

Search terms

Due to well-documented discrepancies in the terminology used in both clinical and research fields related to individuals with ID (Kavale & Forness, 2000), search terms reflected the wide variety of terminology used to describe the population. Terms included in previously published literature reviews were collated to reduce likelihood of missing any relevant articles. Multiple terms were selected to identify staff perceptions, particularly how these were represented in quantitative and qualitative studies. See Appendix A for full details of search terms.

Search limiters

Initial search results were limited to include only: studies published in English, studies published between the year 2000 and the date of the search, articles with full text availability, and articles in dissertation/thesis, journal or review format. The year 2000 was chosen to include articles published both prior to, and following, the publication of the MCA (2005), as it was anticipated that staff perspectives may have been influenced by the changes in legislation. It was hoped that a period of 15 years would enable the findings to remain current with regards to service context and policy.
Inclusion and exclusion criteria

The criteria specified in Table 1 were applied when reviewing titles and abstracts of articles identified in the preliminary search. Studies that did not focus solely on identified characteristics were still included if the results were separable.
Table 1

Inclusion and exclusion criteria applied to preliminary search results to yield relevant studies

<table>
<thead>
<tr>
<th>Criterion</th>
<th>Inclusion</th>
<th>Exclusion</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Population</strong></td>
<td>Paid staff and carers supporting individuals</td>
<td>Unpaid or family carers</td>
<td>The current review seeks only to explore paid staff views</td>
</tr>
<tr>
<td><strong>Characteristics of interest</strong></td>
<td>Account focussed on staff first-person views</td>
<td>Account not focussed on staff narratives</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Adults with ID identified through formal psychometric testing, or intimated by inclusion within specialist ID services</td>
<td>Adults without ID, service users under the age of 18</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sexually offending type behaviour, or sexually inappropriate behaviour, however classified</td>
<td>Non sexual offending type behaviour, or non-sexual challenging behaviour</td>
<td>A variety of terminology is required due to the different way behaviour is constructed within services, and therefore referenced in research.</td>
</tr>
<tr>
<td><strong>Setting</strong></td>
<td>Forensic or secure settings, e.g. prison community ID services</td>
<td>Services not specific to supporting individuals with ID</td>
<td>Due to exploring general staff perspectives, this needs to be specific to individuals supporting only those with IDs</td>
</tr>
<tr>
<td><strong>Date</strong></td>
<td>Studies published between the year 2000 and date of the search (15/5/2015). Further searches were carried out to ensure that no additional papers were published prior to submission.</td>
<td>Studies published prior to the year 2000, or after the search is conducted</td>
<td>The introduction of the Mental Capacity Act in 2005 may impact on staff response due to legal requirements, therefore consideration was given to studies prior to this date to allow for any changes in perception prior to, and following, this development</td>
</tr>
<tr>
<td><strong>Language</strong></td>
<td>Studies published in English language</td>
<td>Studies not published in English language</td>
<td>Time and financial restrictions will not allow for translation</td>
</tr>
<tr>
<td><strong>Country of origin</strong></td>
<td>Studies originating in the United Kingdom</td>
<td>Studies not originating in the United Kingdom</td>
<td>Staff and service users not living within the United Kingdom will be subject to different legal requirements and restrictions, and therefore will not be relevant to the current review and its implications</td>
</tr>
</tbody>
</table>
Selection of studies

Titles and abstracts of studies identified through electronic searching were reviewed to determine potential for inclusion in the review. This was carried out independently by two researchers, and discrepancies in initial judgements were resolved through reviewing the full article. Full text copies of all articles resulting from the initial screen were obtained, and comprehensively reviewed for final inclusion by the lead researcher. Details of studies excluded from the review, at all stages of the selection process, are presented in a flow diagram in line with PRISMA (2009) recommendations (see Figure 1).

Following identification of final studies, eminent published researchers in the field were consulted regarding further potential articles, however this revealed no further results.

Data extraction

An idiographic data extraction table was used for recording and storing pertinent information from the papers included in the review. Data extraction was undertaken by the lead researcher, and verified for accuracy by a second researcher. Details of the study characteristics, staff information, service user information and results can be found in tables 2, 3, 4 and 5 respectively.

Quality assessment

Quality assessment was carried out to aid analysis of study findings, and consider applicability of findings for future clinical and research practice. No numerical cut-off was used to judge quality, as qualitative considerations were deemed more useful, and no studies were rated as being of poor enough quality to warrant exclusion from the review. The quality assessment was used to inform relevance and applicability of findings, and is considered further in the discussion. Due to the combination of both qualitative and quantitative articles identified during the search, flexibility was imperative when reviewing the quality of included articles. Qualitative articles were assessed using the Critical Appraisal Skills Programme (CASP, 2013) checklist for qualitative research (Appendix B), due to being designed specifically to enable clinicians to evaluate the utility and quality of findings (Boland, Cherry & Dickson, 2013). The Newcastle-Ottawa Scale adapted for
cross-sectional studies (Herzog et al., 2013; Appendix C) was used for quantitative studies due to its wide use in research fields, and ability to make adaptations to improve applicability (Boland, Cherry & Dickson, 2013). Quality assessment was carried out by the lead researcher, and results are presented in Tables 6 and 7.
<table>
<thead>
<tr>
<th>Reference</th>
<th>Design</th>
<th>Study aims</th>
<th>Inclusion criteria</th>
<th>Sampling</th>
<th>Percentage response rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smith &amp; Willner (2004)</td>
<td>Cross-sectional quantitative</td>
<td>To study the responses of direct care staff (DCS) and care managers (CM) to inappropriate sexual behaviour depicted in vignettes</td>
<td>Participants all had experience working with men with ID who have displayed SOTB.</td>
<td>Opportunistic sampling, opt-in through response to questionnaire pack</td>
<td>71% CM, 53% DCS</td>
</tr>
<tr>
<td>MacKinlay &amp; Langdon (2009)</td>
<td>Cross-sectional related samples design</td>
<td>To examine the attributions staff make about: (1) Challenging behaviour (CB) (2) previous sex offending behaviour of men with ID; and (3) consider whether attributions vary with the level of ID or seriousness of the offence</td>
<td>Participants must be 'key-worker' for male client with ID for a minimum of 6 months. Service users supported by participants must have a history of sexual offending and a history of challenging behaviour within the last three months.</td>
<td>Opportunistic sampling based on meeting criteria</td>
<td>Not reported</td>
</tr>
<tr>
<td>Willner &amp; Smith (2008)</td>
<td>Cross-sectional quantitative</td>
<td>To examine the applicability of attribution theory to carer's propensity and motivation to support men with ID and SOTB.</td>
<td>Participants all had experience working with men with ID who have displayed SOTB.</td>
<td>Opportunistic sampling, opt-in through response to questionnaire pack</td>
<td>71% CM, 51% DCS</td>
</tr>
<tr>
<td>McKenzie et al. (2001)</td>
<td>Cross-sectional quantitative</td>
<td>To examine the number of care staff with experience of supporting clients with ID and SOTB. Staff feelings towards the client and behaviour, staff confidence and perceived difficulties in supporting clients, and potential support required.</td>
<td>Participants were asked whether they supported individuals with SOTB history; only those identifying experience in this regard were included in analysis of results</td>
<td>Opportunistic sampling; staff in two services known to authors approached to participate</td>
<td>68% healthcare staff (HCS) and 100% social care staff (SCS)</td>
</tr>
<tr>
<td>McBrien &amp; Murphy (2006)</td>
<td>Cross-sectional quantitative</td>
<td>To explore and contrast the attributions and emotional responses of carers and police, towards perpetrators of rape and other offenses, with and without ID.</td>
<td>Care staff: supporting individuals with ID, no other details reported. Police officers: all uniformed police constables (PCs) responding to public calls, no further criteria reported</td>
<td>Convenience sampling; homes known to authors through professional contacts</td>
<td>Carers represented staff from 21% of residential homes in the locality, although unclear what proportion this comprised of staff in total. Police: 100% of those approached participated.</td>
</tr>
</tbody>
</table>
Table 2.

<table>
<thead>
<tr>
<th>Reference</th>
<th>Design</th>
<th>Study aims</th>
<th>Inclusion criteria</th>
<th>Sampling</th>
<th>Percentage response rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Robertson &amp; Clegg (2002)</td>
<td>Qualitative</td>
<td>To explore staff attributions towards risk appraisals of men with ID who have sexually offended</td>
<td>Qualified social workers and community nurses who had experience of sex offending in men with ID</td>
<td>Opportunity sampling approaching community staff known to the researchers</td>
<td>26% approached meet criteria, another 13% declined to participate, 61% not eligible</td>
</tr>
<tr>
<td>Sandhu, Rose, Rostill-Brookes &amp;</td>
<td>Qualitative</td>
<td>To explore experiences of staff working on a treatment programme for sex offenders with ID (adapted SOTP)</td>
<td>Staff working as tutors on the adapted SOTP, therefore having extensive experience working with men who have sexually offended</td>
<td>Purposive sampling within the first author’s professional context</td>
<td>Staff comprised 75% total target population, although unclear whether remaining 25% were approached to participate</td>
</tr>
</tbody>
</table>
Participant (staff) information.

Table 4.

Characteristics of service users supported.

<table>
<thead>
<tr>
<th>Reference</th>
<th>Setting</th>
<th>Designation / qualification</th>
<th>% male</th>
<th>Years of experience</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smith &amp; Willner (2004)</td>
<td>CM: community support teams, DSC: residential care companies</td>
<td>CM = 65, DCS = 56, Total = 121</td>
<td>CM = 31% DCS = 57%</td>
<td>CM median 11-15 years, DCM median 6-10 years</td>
<td>CM median age 38, DCS median age 43</td>
</tr>
<tr>
<td>MacKinlay &amp; Langdon (2009)</td>
<td>Secure forensic service for people with ID detained under MHA due to sexual offending</td>
<td>48</td>
<td>46%</td>
<td>Not reported</td>
<td>Not reported</td>
</tr>
<tr>
<td>Willner &amp; Smith (2008)</td>
<td>CM: community support teams, DSC: residential care companies</td>
<td>CM = 65, DCS = 56, Total = 121</td>
<td>CM = 31% DCS = 57%</td>
<td>CM median 11-15 years, DCM median 6-10 years</td>
<td>CM = median age 38, DCS = median age 43</td>
</tr>
<tr>
<td>McKenzie et al. (2001)</td>
<td>SCS: private provider residential ID setting, HCS: secure community ID accommodation for clients with sexual offending history</td>
<td>SCS = 48, HCS = 15, total = 63</td>
<td>SCS = 42% HCS = 40%</td>
<td>SCS 8.2 years (SD=5.9), HCS 13.6 years (SD=5.8)</td>
<td>SCS mean age = 36.7 years (SD=9.3), HCS mean age = 33.8 years (SD=7.6)</td>
</tr>
<tr>
<td>McBrien &amp; Murphy (2006)</td>
<td>Private and voluntary sector community accommodation for individuals with ID. Comparator group: police officers from local force.</td>
<td>Carers = 80, police = 65</td>
<td>Carers = 38%, police = 85%</td>
<td>Not reported for either sample</td>
<td>&quot;Most participants in carer and police officer groups were aged 30-39 years&quot;</td>
</tr>
<tr>
<td>Robertson &amp; Clegg (2002)</td>
<td>Community teams supporting individuals with ID</td>
<td>6</td>
<td>3 community nurses, 3 social workers</td>
<td>83%</td>
<td>Not reported</td>
</tr>
<tr>
<td>Sandhu, Rose, Rostill-Brookes &amp; Thrift (2012)</td>
<td>Forensic service for individuals with ID</td>
<td>8</td>
<td>Tutors on adapted SOTP, 7 healthcare assistants and 1 psychological therapist</td>
<td>63%</td>
<td>Working as a tutor on SO programme: one to ten plus, even spread across brackets</td>
</tr>
</tbody>
</table>
### Analyses

- Smith & Willner (2004): Multiple statistical analyses including 2x2x2 between-subjects MANOVA investigating victim/offense type and staff role, multiple regression analyses. Causal explanations measured through idiographic questionnaire based on previous research findings of causes for ISB, results presented following factor analysis reducing causes to 5 constructs; sexually motivated, attention-seeking, poorly managed, negative emotional state, lack of education. **Main findings:** Cause for concern - No significant difference found between DCS and CM on risk of recurrence of ISB, but CM reported significantly lower perceived seriousness of offence, need for external management, and requirement of supervision compared to DCS. DCS rated behaviour as more likely to be due to poor management, whereas CM rated it as sexually motivated. **Attributions:** - Attributions of internality and stability of behaviour were significantly higher in CM that DCS. DCS also expressed higher levels of disgust and...
### Reference

<table>
<thead>
<tr>
<th>Analyses</th>
<th>Measures</th>
<th>Main findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>regarding 'concern' around behaviour, group-wise comparisons on all dependent variables (DV's). Mediation analyses investigating impact of seriousness of offense and poor management on response topography</td>
<td>attributions measured through Attributional Style Questionnaire (ASQ; Peterson et al., 1982). Cause for concerns and emotional responses utilised 5-point likert-scale, the latter including likelihood of fear, anger, disgust, sympathy and embarrassment. measuring perceived 'seriousness', 'likelihood of recurrence', and 'need for action', while a 4-point scale measured level of supervision required.</td>
<td>embarrassment compared to CM, alongside lower level of sympathy. Across both groups offences against children were considered more serious, and contact-behaviours considered more serious and requiring increased supervision and consequences, in comparison to non-contact behaviours.</td>
</tr>
<tr>
<td>MacKinlay &amp; Langdon (2009)</td>
<td>Quantitative analysis comprising correlations related to attribution</td>
<td>Attributions measured using ASQ (Peterson et al., 1982), with internality and controllability in relation to self (staff) also measured on 7-point Likert-scale.</td>
</tr>
<tr>
<td>Willner &amp; Smith (2008)</td>
<td>Partial correlation coefficients determined relationships between variables, followed by stepwise multiple regression analyses. Mediation analyses investigated models incorporating stability, optimism, effort and controllability.</td>
<td>Causal attributions measured using ASQ (Peterson et al., 1982). Emotional responses of fear, anger, disgust, sympathy and embarrassment measured on 5-point Likert-scale, reduced through factor analysis to negative and positive emotions. Optimism and effort (how likely they are to invest time in supporting the SU) also measured on 5-point Likert-scale.</td>
</tr>
<tr>
<td>McKenzie et al. (2001)</td>
<td>Questionnaires coded to provide quantitative data (no details provided on analysis used), descriptive statistics, percentages and multiple chi-squared tests performed.</td>
<td>Idiographic questionnaire seeking information around training received, difficulty (6-point Likert-scale) and confidence (5-point Likert-scales) in supporting SUs compared to those with non-sexual challenging behaviour. Feelings about the behaviour and the individual were asked in open-ended format, and future</td>
</tr>
</tbody>
</table>
Table 5.

Study data analyses and results.

<table>
<thead>
<tr>
<th>Reference</th>
<th>Analyses</th>
<th>Measures</th>
<th>Main findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>McMinn &amp; Murphy (2006)</td>
<td>Quantitative within and</td>
<td>Questionnaires utilised open-ended questions (responses then coded thematically) regarding report of offense, and what the perceived consequences would be for the offender, the reporter (carer) and the police response. Attributes were measured by the amended Revised Causal Dimensions Scale II (McCueley, Duncan &amp; Russell, 1992) using 9-point Likert-scale responses for internal control, external control, internality, stability and emotional response of anger/sympathy. Attribution measures compared between groups (police - carers, and ID - non-ID perpetrator).</td>
<td>Carers significantly less likely to report rape offenses to the police when the perpetrator has ID compared to no ID (p&lt;0.05). Carers significantly less likely to believe in reporting rape by perpetrator with ID compared to police (p&lt;0.05). Carers felt that ID perpetrators of rape were more in need of help and understanding, compared to non-ID perpetrators (U=518, p&lt;0.05), whereas police respondents believed that punishment was necessary. Carers believed that ID perpetrators of rape were less likely to be subjected to the CJS compared to non-ID perpetrators (U=460, p&lt;0.001), and carers were significantly less likely than police to believe in pursuing the CJS route for ID perpetrators of rape (U =441, p&lt; 0.01). Staff felt they would be criticised for reporting a rape by a perpetrator with ID. Attribution effects not reported separately for crime (rape, theft and assault calculated together) but no overall significant effects of ID on internal control, overall significantly more sympathetic to ID compared with non-ID perpetrators (no P values reported).</td>
</tr>
<tr>
<td>Robertson &amp; Clegg (2002)</td>
<td>Qualitative interviews undertaken, data subsequently analysed using quantitative coding</td>
<td>Interview transcripts coded using Leeds Attributional Coding System (LACS) (Munton et al., 1999) to reveal statements related to stable/unstable, global/specific, internal/external, personal/universal and controllable/uncontrollable attributions. Global/specific and stable/unstable subsequently excluded due to low reliability.</td>
<td>In total 371 attribution statements made, 147 related to appraisal of SOTB or risk. Factors reported in relation to ‘internal/external influences on participants’ and ‘internal/external influences on service-users’. Factors decreasing confidence in risk assessment included other staff minimising the severity of behaviour and not developing care plans, information not recorded appropriately and lack of support from others/management. External control was important in managing reoffending risk, including environmental management and supervision. Factors internal to the SU which eroded confidence in risk judgements included displaying a pleasant persona and hiding offense-related attitudes. Holding inappropriate attitudes, loitering opportunistically and rationalising offences were considered to indicate SU’s increased control over their behaviour. Overall, risk management was equally reliant on internal and external factors, but external factors were more often stated as causes of SOTB.</td>
</tr>
</tbody>
</table>
Reference Study data analyses and results

<table>
<thead>
<tr>
<th>Analyses</th>
<th>Measures</th>
<th>Main findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sandhu, Rose, Rostill-Brookes &amp; Thrift (2012)</td>
<td>Interpretative phenomenological analysis used to analyse open-ended interviews regarding experiences working on the programme, responses to the type of work, and feelings about sexual offending and ID.</td>
<td>The themes arising were: first; &quot;the empathy challenge&quot;: struggling to support individuals with no empathy for victims, while becoming overwhelmed with empathy for the victims themselves, compartmentalising the offense and holding in mind the perpetrator's position as both offender and victim. Second theme: &quot;it’s intense, to an extent&quot; (emotional responses): included feeling distressed, upset, disgusted at offenders and pessimism regarding treatment. Third theme: &quot;dealing with the emotional challenges&quot; emotional distance and dissociation as a defence, becoming desensitised to the offences. Self protection enabled continuity of work, while peer supervision and support was considered imperative for dealing with emotional challenges.</td>
</tr>
</tbody>
</table>
Table 6.
Quantitative quality assessment table – using the Newcastle-Ottawa Scale adapted for cross-sectional studies (Herzog et al., 2013)

<table>
<thead>
<tr>
<th>Study</th>
<th>Selection process (total 5*: star rating system used throughout)</th>
<th>Comparability (total 2*)</th>
<th>Outcome (total 2*)</th>
<th>Overall (total 9*)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Representativeness of sample*</td>
<td>Sample size justified and satisfactory*</td>
<td>Satisfactory response rate*</td>
<td>Validated measurement tool **, or described in detail *</td>
</tr>
<tr>
<td>Smith and Willner (2004)</td>
<td>No description of sampling</td>
<td>Not justified</td>
<td>Response rate satisfactory *</td>
<td>Validated **</td>
</tr>
<tr>
<td>Mackinlay and Langdon (2009)</td>
<td>Non-random sampling, but target population discussed represented*</td>
<td>Not justified</td>
<td>No description of response rate *</td>
<td>Validated **</td>
</tr>
<tr>
<td>Willner and Smith (2008)</td>
<td>No description of sampling</td>
<td>Not justified</td>
<td>Response rate satisfactory *</td>
<td>Validated ** and other factors described</td>
</tr>
<tr>
<td>McKenzie et al. (2001)</td>
<td>Non-random sampling*</td>
<td>Not justified</td>
<td>No description of response rate</td>
<td>Described *</td>
</tr>
<tr>
<td>McBrien and Murphy (2006)</td>
<td>Unclear how selected</td>
<td>Not justified</td>
<td>Response rate satisfactory, *</td>
<td>Described *</td>
</tr>
</tbody>
</table>
Table 7.

<table>
<thead>
<tr>
<th>Study</th>
<th>Clear statement of aims?</th>
<th>Qualitative methodology appropriate?</th>
<th>Research design appropriate to aims?</th>
<th>Recruitment strategy appropriate and clear?</th>
<th>Data collection adequate to address question?</th>
<th>Relationship between researcher and respondents addressed?</th>
<th>Clarity around ethical issues?</th>
<th>Data analysis sufficiently rigorous?</th>
<th>Clear statement of findings?</th>
<th>How valuable is the research?</th>
<th>Other comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Robertson and Clegg (2002)</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No; no reflection on role or position working within same service and implications</td>
<td>Ethics approval confirmed, but no other discussion</td>
<td>Unclear. Quantitative coding process used, role and bias not considered.</td>
<td>Clear findings, but lack of evidence of credibility, only one research involved in analysis</td>
<td>Contribution explored, linked to literature base. No further research directions covered.</td>
<td>Qualitative data collection but quantitative coding used. Answered research question, but potential for missing valuable information</td>
</tr>
<tr>
<td>Sandhu et al. (2012)</td>
<td>Yes but only in abstract</td>
<td>Yes</td>
<td>Yes</td>
<td>Appears appropriate, but no discussion of 25% that did not take part or potential missing themes</td>
<td>Yes</td>
<td>No. Discussion of IPA in relation to methodological limitations, but no mention of researcher’s role or position</td>
<td>No, other than ethical approval gained</td>
<td>Yes</td>
<td>Yes</td>
<td>Numerous useful implications for both service users and staff in service development. No future research directions.</td>
<td>Reflection on researcher’s role as Trainee Clinical Psychologist, enquiring about psychological issues, would have been beneficial.</td>
</tr>
</tbody>
</table>
Results

In total, seven papers were included in the final analysis, comprising five quantitative and two qualitative studies. Four studies were carried out in community settings, two in forensic environments, and one study compared staff groups across both settings. The most common quantitative measure used was the Attributional Style Questionnaire (Peterson et al., 1982) used in three studies, the Revised Causal Dimensions Scale II (McCauley et al., 1992) was used in one study, and one interview study employed the Leeds Attributional Coding System (Munton et al., 1999) to code qualitative data.

A number of similarities emerged across the papers, irrespective of methodological approach, and therefore the themes apparent in the results will be discussed with respect to the totality of papers reviewed. Papers included references to perpetrators of both alleged and proven offences, and therefore the term sexual offending type behaviour (SOTB) will be used to encompass behaviours falling under both legal definitions.

Attributions

Four of the studies utilised measures of attribution style to explore staff perceptions of SOTB, three (MacKinlay & Langdon, 2009; Smith & Willner, 2004; Willner & Smith, 2008) employing the Attributional Style Questionnaire (Petersen et al., 1982) while one undertook attributional coding of qualitative interview data (Robertson & Clegg, 2002). Not all attributional elements were reported in each study, (for example Robertson and Clegg found limited reliability for coding related to stable/unstable and global/specific, so excluded these elements), and those reported often varied.

Sexual offending-type behaviours were often perceived as stable to the client (MacKinlay & Langdon, 2009; Smith & Willner, 2004; Willner & Smith, 2008), indicating that changes in behaviour would not be possible. In one study this was linked to decreased optimism for the likelihood of successful treatment (Willner & Smith, 2008). Victim type also influenced attributions of stability, as SOTBs committed against child victims were considered more stable, and therefore potentially more persistent, than those committed against adult victims (Smith & Willner, 2004).
In contrast to the consistency noted with regards to attributions of stability, perceived internality of behaviour varied between respondents and studies, with little consensus between staff groups. Some studies revealed that SOTB was attributed as more internal to the service user, and less contingent on external influence (MacKinlay & Langdon, 2009; Smith & Willner, 2004), while other results revealed greater emphasis on external management strategies and environmental controls (Smith & Willner, 2004; Robertson & Clegg, 2002). In some cases this discrepancy was contingent on position of staff, with those directly involved in supporting the service users placing higher emphasis on external influences such as poor management (Smith & Willner, 2004), while indirect care managers were more likely to emphasise internal causative factors, reducing the requirement for external supervision and management.

Controllability of behaviour was also reported by four of the studies, yet results again varied dramatically between these. In some cases, SOTB was seen as neither controllable nor uncontrollable by the SU, but as wholly uncontrollable by the staff team (MacKinlay & Langdon, 2009), while other staff reported that SOTB was controllable by the service user, and this was associated with increased seriousness of the behaviour, and increased need for supervision and management (Smith & Willner, 2004). In contrast to these findings however, Willner and Smith (2008) found no relationship between perceived controllability on anger or sympathy experienced by staff, or on their propensity to invest effort in helping service users alter their behaviour.

Qualitative data collected by Robertson and Clegg (2002) provides contextual richness to the quantitative findings above. With regards to internality of behaviour, staff identified both internal and external factors as important considerations for risk management, however external influences such as a failure in external supervision were seen as paramount in allowing SOTB to occur. They also found that control over behaviour was not consistent across all individuals and behaviours, but varied in relation to specific SOTB features. These included perceptions that behaviour was more controllable if it was accompanied by holding and hiding attitudes that condoned SOTB, and behaviour that indicated planning, such as loitering in an opportunistic manner. These factors were also linked to reduced confidence in the ability of staff to manage future risk.
Emotional responses to behaviour

Five studies reported effects of SOTB on staff emotional experience, and the resulting impact of these emotions on management strategies. Sympathy was reported by Willner and Smith (2008) as influential on the level of optimism staff had for SU, alongside the level of effort staff invested in supporting the SUs. Sympathy was also noted in McBrien and Murphy’s (2006) study, finding that staff expressed more sympathy in relation to perpetrators of rape with ID, in comparison to those without ID. This was associated with perceptions that the individual with ID was vulnerable, thereby in need of help and understanding rather than punishment.

Although sympathy for service users was reported by a number of studies, reports of negative emotional experiences such as disgust, anger and embarrassment were also discussed in four studies. McKenzie et al. (2001) found that staff experienced disgust and anger towards both the individuals they supported, and the behaviours displayed, although this differed between staff group: social care staff working in the community experienced negative emotions towards the behaviour, while healthcare staff in the forensic setting felt negatively towards the individuals themselves. This difference was potentially due to the offending patterns: those in the healthcare setting required increased security, and it would be inferred that this could be due to riskier SOTB. Both groups found that their own, and others’ negative attitudes towards the SUs were particularly difficult to manage.

Further to the differences in attributional style reported by direct and indirect staff, direct care staff also experienced increased disgust and anger towards SUs, in comparison to non-direct management staff (Smith & Willner, 2004). For both direct and indirect staff, ratings of anger were correlated with perceived seriousness of the behaviour perpetrated. Higher ratings of disgust also correlated with reduced sympathy for SUs, and this was in turn related to an increased need for external supervision and punitive management strategies. More generally, emotional experiences were considered to be both frequent and intense when working with this population, with staff commonly reporting negative emotional states (e.g. Smith & Willner, 2004).

Both qualitative studies also emphasised the intense emotional impact of the work, with staff often experiencing overwhelming and complex emotional reactions (Sandhu et al., 2012). These
included feelings of disgust at particular SUs, while also noting anger and frustration at other members of the treatment groups. As a form of protection staff tended to distance themselves from, or deny emotional responses to, the SUs, due to the potential for these to become overwhelming (Sandhu et al., 2012). Robertson and Clegg (2002) also highlighted emotional challenges, with staff reporting feeling nervous with regards to the inherent risks associated with supporting this client group (Robertson & Clegg, 2002).

Alongside more difficult emotional experiences, Sandhu et al. (2012) revealed that staff experienced complex empathic responses towards service users and their victims, named “the empathy challenge”. The process of separating the person from their behaviour facilitated an empathic response, holding in mind the SU’s frequent position as a victim, as well as perpetrator, of sexual abuse.

The focus on emotional experiences in both interview studies may reflect the position of the researchers, who were Clinical Psychologists working within the same service as the respondents. As such, participants may have been innately primed to reflect on emotional aspects due to the nature of their usual interactions with the researchers. While this may be intimated from the research, neither study explicitly considered the researchers’ position, or the impact this may have had on responses in the interviews.

Impact of ID

Despite the focus on staff supporting individuals with ID, the nature or characteristics of individuals’ diagnoses were rarely explicitly reported in relation to their SOTB. MacKinlay and Langdon (2009) found a significant effect of IQ on staff attributions with regards to behaviour: service users with higher intellectual functioning were perceived as having greater controllability over their behaviour, and their SOTB was seen as internal to them. McBrien and Murphy (2006) specifically compared vignettes of ID with non-ID offenders, finding that care staff stated they would be significantly less likely to report rape offences to the police if perpetrated by an individual with ID. These staff also predicted that perpetrators with ID would be less likely to be subjected to CJS proceedings than non-ID counterparts, although police respondents did not share this view. Carers felt
that perpetrators with ID were more vulnerable and in need of help, rather than punishment, compared to perpetrators of similar behaviours without ID. Smith and Willner (2004) explored causal explanations of behaviour related to lacking knowledge and skills in their data collection (potentially related to ID), however results related to these factors were either not identified by staff members as explaining behaviour, or not reported.

Interestingly, the qualitative studies did not report specifically on aspects related to the SU’s ID. This might indicate that, unless explicitly brought to staff’s attention through the research process, the SUs ID did not influence staff perceptions to an extent worthy of noting in the analysis. Alternatively, the researchers’ position as an employee within the service may have negated the need for explicit reference during interview.

Perceptions of risk

Three of the studies referred explicitly to factors influencing risk of SOTB recurrence, alongside staff confidence in managing this risk. Risk was primarily attributed to factors outside of SU’s control (Smith & Willner, 2004; Robertson & Clegg, 2002), however Robertson and Clegg (2002) also found perceptions of increased risk due to SUs hiding true attitudes towards sexual behaviours. There was again some discrepancy between direct and indirect staff (Smith & Willner, 2004), as managerial staff placed more emphasis on internal motivation, in contrast to direct staff emphasising failures in external management. Robertson and Clegg (2002) found that risk was perceived to be increased by other staff members minimising both the risks posed by service users, and their responsibility for their behaviour. This resulted in pertinent information not being recorded appropriately, and a failure to develop or implement adequate risk management plans (Robertson & Clegg, 2002). Alongside these concerns that staff under-estimated service users’ risk, McKenzie et al (2001) reported concerns around service users minimising their responsibility for their behaviour, which created increased staff concern, and greater difficulty in supporting the client group.
Influence of training

Although this was not explicitly reported in the majority of studies, the influence of training, or lack thereof, is important to consider. Training can significantly enhance staff confidence in supporting SU with complex needs (Tierney, Quinlan & Hastings, 2007), however the impact of this on SU care is less clear cut (McDonnell et al., 2007). The complex relationship between training and quality of care therefore requires further consideration.

While Robertson and Clegg (2002) reported participants’ exposure to training, this was not specifically considered in relation to their results. It was noted, however, that allocation of staff to support perpetrators of SOTB was often on the basis of gender rather than skills or experience, and that participants considered the lack of specialist training an important influence on confidence levels. McKenzie et al (2001) found that staff indicated a need for further specialist training regarding theoretical understanding and effective therapeutic approaches. Despite this, their results revealed no effect of level of previous training on confidence in managing risk, perceived difficulty of the work, or attitude towards the SUs or their behaviour. This not only indicates a lack of confidence in managing the SOTB, but also suggests they lack clarity around how to remedy these difficulties.
Discussion

The current review aimed to explore staff views and experiences of SOTBs displayed by service users with ID within their care. The literature search revealed few studies looking specifically at this phenomenon, with the majority of research focussing on either responses to victims of such behaviours, or approaches to remediate the SOTB. The five quantitative and two qualitative studies included in the review focussed predominantly on attributions of behaviour, including whether it was considered controllable by the perpetrator and the influence of internal or external factors on risk of recurrence. There was also exploration of the emotional toll on carers, and the impact of the presence of ID, with consideration of how these factors influence likely staff responses to SOTB. The discussion will consider implications of the findings on future clinical and research practice, alongside reflecting on the differences seen between study findings, reasons that could explain these differences, and implications arising from the inconsistencies.

There were some areas of consensus between the studies, for example finding that alleged perpetrators with ID are often viewed more sympathetically than those without ID, with less control over, and potentially less responsibility for, their behaviour. The implications of such views appear to indicate that staff may minimise, or fail to respond to, behaviours that could otherwise pose a risk to society. It has consistently been shown in previous research that a failure to respond to SOTB paves the way for repeat offending, through a lack of consequences for behaviour, and reduced opportunities to access therapeutic interventions aimed at reducing offending (McBrien & Murphy, 2006).

The consequences of failing to provide adequate intervention strategies are demonstrated clearly in the literature: Lindsay, Steele, Smith, Quinn and Allan (2006) found worryingly high recidivism rates of 24% in a community sample of men who displayed SOTB with no supervision or intervention, compared to rates of 10.7% for those with limitations imposed (McGrath, Livingston & Falk, 2007). With this in mind, it is important to tackle attitudes that minimise the severity of such behaviours, and increase understanding of the importance of both internally- and externally-focussed interventions to prevent future offending.
Differences between results

Alongside the similarities between results presented above, there were also considerable discrepancies in the findings. The difference in attribution between direct and management staff regarding internality of behaviour (Smith & Willner, 2004) therefore has implications for potential intervention. Care managers' reductionist view of behaviour as solely internal to the service user could perhaps be influenced by the resulting lack of necessity for costly external management strategies. However, this would also preclude the use of interventions incorporating external elements such as the ‘Good Lives’ model (e.g. Ward & Siegert, 2002). Conversely, attributing the behaviour to external factors, as in the case of the direct care staff, reduces individual culpability. In this regard, approaches developing socio-affective skills and targeting offence-supportive cognition (as in many approaches to ID SOTB; Williams & Mann, 2010) may not be pursued.

Other discrepancies arose between studies reporting on similar constructs, which may reflect the variety of methodologies employed. Robertson and Clegg (2002) reported that some coding undertaken during their study using the Leeds Attributional Coding System (Munton et al., 1999) yielded unreliable data, which was subsequently excluded from their analysis. They also noted that quantitative attribution measures provide restricted possibilities for response, thus curtailing the range of potential responses (Robertson & Clegg, 2002). As such, the quality of information obtained through attribution measures is restricted. Further to this, three studies undertook coding of qualitative data (McKenzie et al., 2001; Robertson & Clegg, 2002; Sandhu et al., 2012) which, by its very nature, may introduce an element of bias into the results, dependent on the analyst’s stance on the subject. Exacerbating the possibility of bias is the undisclosed coding method used by McKenzie et al. (2001) to code qualitative data from open-ended questions used in their study. The position of the researchers in these three studies may therefore have influenced the results, and although this possibility was acknowledged in two papers (Robertson & Clegg, 2002; Sandhu et al., 2012), position statements were not offered to clarify any potential influence.

The discrepancy in results may also be indicative of factors inherent to the populations studied: for example, local policy or service culture may influence how behaviour is perceived, and
inform both individual, and service level, responses. The perception of SOTB, and implications for judging potential risk to others, is imperative to consider, given the dual role for services of balancing normalisation of life experiences (such as rights to sexual and romantic relationships) with protection of the individual and others (Manthorpe, Walsh, Alaszewski and Harrison, 1997).

With the exception of the Assessment of Risk and Manageability for Individuals who Offend Sexually (ARMIDilo-S; Boer, Tough & Haaven, 2004), no validated measures of dynamic risk for individuals with ID who display SOTB exist (Lofthouse et al., 2013), therefore perceptions of risk within services often rely solely on staff clinical perspectives. The extent to which SOTB are therefore deemed as risky, or in need of a response, is likely to differ based on cultural values and the individuals involved. This is particularly visible in the differences documented by Smith and Willner (2008) between views held by those responsible for making, and implementing, risk-related decisions. It may be pertinent for future research to explore whether perceptions are influenced by experience of undertaking structured professional judgement risk assessments. Training in understanding evidence based risk factors may improve the accuracy and relevance of causal attributions, and the resulting consistency of response.

The impact of terminology

Differences in ways of viewing behaviour in services may also be influenced by its construction through language in different contexts. While this may have affected the consistency of results within the current review, alongside affecting the likelihood of being able to collate all relevant studies within the literature, there are more serious implications for construction of SOTB within services.

Throughout the included studies, and those excluded at earlier stages of the review, a vast range of terms were used to describe SOTB, including offending, inappropriate sexual behaviour, sexualised challenging behaviour and sexual abuse. Doyle (2004) discusses the linguistic nuances which often influence responses to SOTB, indicating that behaviour termed as “challenging” rather than “offensive” will elicit a different service response. Lockhart, Guerin, Shanahan and Coyle (2009) also differentiate between offending, and non-offending behaviour, based on the perpetrator’s
understanding of such, and legal implications related to criminal intent. While these are relevant considerations, decisions as to intent, or culpability should not be made by care staff, as McBrien and Murphy’s (2006) findings indicate, but by legal and clinical professionals when considering diversion from the CJS, as emphasised in Lord Bradley’s report (DoH, 2009).

The attributions staff make towards SOTB, and terminology used to construct the phenomenon, may go some way to explaining the delay often seen in referring perpetrators to intervention programmes (Heaton & Murphy, 2013). Alongside this, however, there is the emotional impact of such work on staff to consider.

The double-edged sword of empathy

It has long been noted that men who commit SOTB have often been victimised themselves (Glasser et al., 2001; Lindsay, Law, Quinn, Smart & Smith, 2001). Known as the ‘cycle of child abuse’ this theoretical underpinning is reflected in the current results, and may go some way to explaining the lack of a consistent approach to men with ID who perpetrate SOTB. The study by Sandhu et al. (2001) revealed some degree of empathy for the perpetrators due to their own abusive histories, while McBrien and Murphy (2006) reported views that the perpetrators were vulnerable individuals in need of help rather than punishment. This reflects Fyson’s (2007) finding that staff within schools for adolescents with ID were hesitant to report SOTB, due to concerns that the perpetrator would be labelled as a sex-offender, with negative implications. Staff may therefore hope that their leniency affords the perpetrators a deserved reprieve, however this denial of responsibility may also perform a function for the staff themselves.

The emotional impact of supporting an individual displaying SOTB was reported in the majority of studies in the review. From disgust and embarrassment at the offender and their behaviour (MacKenzie et al., 2001; Willner & Smith, 2004) and a fear of becoming overwhelmed by the gravity of the behaviour (Sandhu et al., 2012), minimising the culpability of the perpetrator may enable the carer to provide the necessary empathic support which may, otherwise, not be possible. Burnout (e.g. Maslach & Jackson, 1981), is a process by which staff or carers become overwhelmed with emotion, are at risk of depersonalising their clients, and receive little positive reward for their work. Burnout is
acknowledged as plaguing many staff working in ID settings (Hastings, Horne & Mitchell, 2004) and the added emotional impact of supporting individuals with SOTB could jeopardise both staff, and service user, well-being. Strategies to improve staff well-being and confidence in managing risk are imperative in such services. These could include training packages aimed at understanding theoretical and professional issues inherent within the role (Taylor, Keddie & Lee, 2003), or informal peer support to manage emotional responses to clinical work (Sandhu et al., 2012), which have both been reported as beneficial in these settings.

The emotional toll on workers revealed in both the current, and previous literature, is unsurprising considering the lack of policies and guidance available to staff supporting men with SOTB (Lyall, Holland & Collins, 1995; McBrien & Murphy, 2006). Without a consistent approach, carers face intense uncertainty regarding how to respond to SOTB, evidenced by anticipating criticism and negative repercussions should they report alleged offences to the police (McKenzie et al., 2001). Alongside this, research has shown that ambiguity or inconsistency in response to criminal or offensive behaviours provide little deterrent against committing future offences (Loughran, Paternoster, Piquero & Pogarsky, 2011). As such, the lack of consistency within service responses could have a detrimental effect on future offending trajectories. In this regard, it is imperative for services to develop formal procedural guidance, informed by evidence-based practice and legal guidelines, to ensure a consistent response for SUs, and increased staff confidence.

Future research directions

The quality assessment tools used to evaluate the above studies revealed little difference in terms of robustness and value. Due to the nature of the studies, standard cross-sectional quality assessment tools were limited in their applicability, but did note aspects to be considered by future researchers. For example, the total number of staff from which the respondents were selected was often not declared, thus giving no indication of the representativeness of the sample. Similarly, characteristics of non-respondents were often not declared, or considered in the papers’ discussions, therefore other perspectives may have been missed.
The proportion of studies utilising qualitative methodologies was also limited, resulting in minimal explanation of the phenomena identified by the quantitative research. Robertson and Clegg’s (2002) qualitative study also used an attribution measure to code their data, thus potentially restricting the repertoire of given responses, and again limiting the explanatory utility of the results. Future qualitative research could explore staff understandings of the perceptions they, or other staff, hold regarding the trajectories that should be pursued in the event of SOTB occurring. Understanding personal experiences, and related motivations, could shape training- or supervision-led interventions to improve staff reflective capacity, and confidence in managing such situations.

Given the variety of language used to construct SOTB throughout the studies in the review, it may be helpful to consider whether the differences in terminology impact on responses to SOTB. Future research could employ a vignette design to manipulate the terminology used to describe such behaviour, and explore any implications for staff responses. Alternatively, factors affecting how behaviour is constructed (e.g. as challenging or offensive) could be explored.

It may also be worthwhile considering the terminology used to portray aspects of sexuality and sexual behaviour in everyday conversations. Marshall (2005) discusses how therapist style in sex offender treatment influences outcomes, while Sandhu et al. (2012) consider the process issues inherent in the “key role that therapists play” in shaping men’s constructions around SOTB (pp. 308). In this regard, research exploring staff discourse around sex and SOTB in everyday interactions, could inform development of ID services where sex and interpersonal interactions are constructed in a healthy, and accessible, manner.
References


Chapter Two

“They just said inappropriate contact.”

What do service users hear when staff talk about sex and relationships?²

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Abstract

Background

People with intellectual disabilities (ID) often feel restricted in pursuing intimate relationships, particularly in care settings. Research into staff views has revealed a complex picture of conservative perspectives, with some more recent improvement towards acceptance of sexuality and ID. The current study examines service user experience of discourses and perceived staff talk about sexuality and intimate relationships”

Method

Using critical discourse analysis, semi-structured interviews with eight service users revealed 11 themes related to discourses prevalent within a secure hospital, which fell into three broad categories.

Results

Identified functions of the discourses included maintaining the integrity of the institution, and enabling staff to occupy a position of power. A third category relating to service users’ responses to perceived control was also dominant in the narratives.

Conclusions

Discourses around sex appear to serve the interests of staff and the hospital, while being restrictive and often incomprehensible to service users. Implications for service development, and future research directions, are considered.

Key terms: intellectual disability, sex, relationships, staff, secure services, critical discourse analysis.
Introduction

The sexuality of individuals with ID\(^3\) remains a contentious and under-researched topic (Friedman et al., 2014). This is particularly notable within care environments, where staff are often unclear as to the appropriateness of intimate and sexual relationships, and service users (SUs) feel that staff require further training in order to provide adequate support (Bane et al., 2012).

Over recent decades, increased consideration of the experiences of SUs has given rise to improvements in ID service provision. For example, since the normalisation principles of the 1970s (e.g. Chappell, 1992), and more recently the development of ‘Valuing People Now’ (Department of Health [DoH], 2009), services are better guided and monitored with regards to the rights and opportunities afforded SUs with ID. Despite these developments, the practices and ethos underpinning institutions supporting individuals with ID have come under increasing scrutiny following the emergence of concerning organisational practice within British ID care services (Flynn & Citarella, 2012; Francis, 2013). It would appear that the act of balancing protective responsibility with service user (SR) rights is difficult to master (Robertson & Collinson, 2011; Sellars, 2011). This is thought to be exacerbated in forensic, or locked environments, where protection of both the individual and the public adds further complexity to decision-making (Hassiotis et al., 2009).

Staff responses to sexuality and ID

Although still limited, the attention given to the sexuality of individuals with ID has grown over recent years (e.g. Rushbrooke et al., 2014). Qualitative exploration with SUs has revealed that historical depictions of ‘eternal children’ (McCarthy, 1999) still abound in contemporary care services, whereby society embraces a ‘protective’ stance by preventing sexual exploration or expression in individuals with ID (Hollomotz, 2009). While this protector role is often elicited by females with ID (Winges-Yanez, 2013), at the other end of the spectrum, research with men has tended to focus on their sexual aggression (e.g. Lunsky et al., 2007) and a perceived inability to

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\(^3\) It is important to raise a reflection on terminology; the term “intellectual disability” (ID) is felt to be reductionist in its representation of the client population, due to the very nature of such difficulties themselves being socially constructed, and not simply an intellectual difficulty. Despite this, the term ID will be used throughout this paper, due the international understanding of the client population, and the use of this terminology within the research field (Shalock et al., 2007).
control sexual urges (McCarthy, 1999). Often restrictive views held by staff are unsupported by theoretical or explanatory reasoning. For example Winges-Yanez (2013) describes her experiences of facing the troubling discourses shared by managerial staff within an ID support service, constructing sex as ‘not right’ for people with ID. Held and disseminated by those responsible for promoting development, rehabilitation and equality, these views may permeate ID institutions and hamper the expression and exploration of sexuality for individuals with ID, consequently perpetuating the staff-SU power imbalance, and reducing well-being (Brodwin & Frederick, 2010).

Quantitative attitudinal research has found that sexuality has more recently been construed from a more accepting and equal perspective (Cuskelly and Gilmore, 2007), with staff holding generally positive views on areas relating to sexual expression, homosexual relationships and masturbation (Cuskelly & Bryde, 2004). This development, however, is potentially context-specific, supporting the influence of social expectations on the rights and needs of others. For example, members of staff supporting ID SUs in the community have been found to hold more liberal views of sexual expression than staff in ‘institutions’ (Grieve et al., 2008).

Service user experience

This purported shift towards acceptance of sexual expression appears not to be reflected in the messages conveyed to SUs. McCarthy (2014) conducted a systematic review of qualitative research exploring the sexual experiences of women with ID, and found consistently negative and oppressive experiences related to both expressing sexual need, and pursuing safe sexual relationships. Also employing a qualitative methodology, Kelly et al. (2009) found that SUs do not feel trusted to have relationships, while Fitzgerald & Withers (2013) reported that women with intellectual disabilities feel that sex is “dirty”, and that they are “not allowed” to engage in sexual behaviour. Terminology such as this indicates an element of prohibition, which is reflective of the more conservative and restrictive practices often previously seen in institutions.
The influence of discourse

Research promoting the rights of people with ID often takes a socially constructed position on disability (e.g. Nunkoosing, 2000; Dudley-Marling, 2004; Scior, 2003). This situates the ‘disability’ not within the individual themselves, but in the interface between the individual and society (Cockain, 2014). Social interactions provide a platform for shaping and reflecting perceptions of disability (Kang, 2009), the very term denoting a deficit or impairment in comparison to the ‘able’ norm. In this regard, language can be seen as creating, or perpetuating, a power imbalance (Fairclough et al., 2011) related to perceived (dis)ability and the implications this has for future opportunities and life choices (Gillman et al., 2000).

Alongside the construct of ID itself being culturally and socially informed, narratives around sex, relationships, and the availability of such for people with ID are also heavily socially influenced (Gougeon, 2009). Sexual meanings and skills are predominantly learnt through social interaction and discourse, (Simon & Gagnon, 2003), while social and cultural context has significant implications for the development of sexual identify (Horowitz & Newcomb, 2002). Within institutions where the majority of interactions include a staff presence, SU development of sexual identity is likely to be heavily influenced by dominant staff narratives on sexuality (Evans et al., 2009). This is particularly pertinent in settings for individuals with ID, due to their increased suggestibility compared to non-ID peers (Gudjonsson & Henry, 2003) and forensic settings where histories of “inappropriate” sexual behaviour are prevalent (Lindsay et al., 2010). It is important to note, however, that the very concept of “inappropriate sexual behaviour” will vary between settings due to the differing constructions of what is considered “inappropriate”

Cuskelly and Bryde (2004) emphasise how negative views of sexuality held by care staff are often internalised by individuals with ID, and that inconsistency in messages regarding sexuality can contribute to a confusing atmosphere for identity development. Messages conveyed through discourse in forensic ID settings may therefore have far-reaching implications for the development of SUs’ sexual understanding and identity.
New directions

Existing research has adopted one of two main foci: staff attitudes towards the sexuality of SUs with ID (e.g. Yool et al., 2003; Gilmore & Chambers, 2010) or SU perspectives of their rights and experiences relating to sexuality (e.g. Fitzgerald & Withers, 2013; Kelly et al., 2009).

As yet, there is a dearth of literature linking these two areas; that is, exploring the ways in which staff narratives are conveyed to SUs through discourse within ID services. There has been an increasing emphasis on relational security and environmental influences on offending (Shuker & Sullivan, 2010; Sarkar & di Lustro, 2011) alongside recognition of the importance of culture in shaping institutional practice (Dixon-Woods et al., 2013). The high intensity of contact with staff within ID settings may exacerbate the influence of prevalent discourses on SU development. Additionally, the function of secure settings indicates there may be additional responsibilities relating to offending behaviour, particularly sexual offending, which are likely to be influenced by the language used to construct sexual ‘realities’ within the environment. As such, exploring the impact this has on SUs’ meaning-making and subsequent behavioural expression (Carter, 2013; Craft & Brown, 1994) is imperative within a service supporting offenders.

Aims

The current study will seek to enhance the existing literature by examining service users’ accounts of the messages around sexuality conveyed by staff within forensic ID services, and the functions of these discourses.
Method

Design

Semi-structured interviews were carried out with individuals with ID, and analysed using the principles of Critical Discourse Analysis (CDA, van Dijk, 2008b). CDA looks at the narratives and discourses used in human interaction, and considers the functions these serve in the speakers’ context. CDA is particularly important in exploring, and preparing for action against, power imbalances within institutions (van Dijk, 2008a), such as those inherent in care services, and considers these within both the immediate and wider socio-psychological context. This provides an added element in comparison to other qualitative approaches, and is consistent with the positioning of the author (see Appendix F).

Participants

Interviews were conducted with eight individuals with ID living in a secure hospital in the North of England. The service supports individuals with a range of mental health and offending needs, including offering adapted sex offender treatment programmes and social opportunities for all SUs, including those who identify as lesbian, gay, bisexual or transgender (LGBT). Inclusion criteria ensured that all participants were over the age of 18, diagnosed with ID, able to consent to the research and did not present an unmanageable physical risk to the interviewer. Additionally, professionals involved in recruitment relied on multi-disciplinary decisions, to try and ensure that potential participants would not become unduly emotionally distressed by the topics covered. The sample size was informed by previous qualitative research exploring topics of sexuality (e.g. Scior, 2003; Fitzgerald & Withers, 2011), and also by the availability of SUs meeting inclusion criteria. It was hoped that this sample size would provide adequately rich data, while enabling a comprehensive analysis to be undertaken.

Table 8 shows demographic characteristics of each respondent, identified by pseudonyms chosen by each participant during the interview process. Initially ten participants were identified, however one female subsequently withdrew consent due to concerns about the recording process, and one female was deemed too unwell to participate.
Table 8
Participant demographic characteristics

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Gender</th>
<th>Sexual orientation</th>
<th>Index offence type</th>
</tr>
</thead>
<tbody>
<tr>
<td>Christian</td>
<td>50-60</td>
<td>Male</td>
<td>Straight</td>
<td>Violent</td>
</tr>
<tr>
<td>Barry</td>
<td>20-30</td>
<td>Male</td>
<td>Straight</td>
<td>Violent</td>
</tr>
<tr>
<td>Mark</td>
<td>30-40</td>
<td>Non-binary</td>
<td>Gay</td>
<td>Sexual</td>
</tr>
<tr>
<td>Sam</td>
<td>20-30</td>
<td>Male</td>
<td>Bisexual</td>
<td>Sexual</td>
</tr>
<tr>
<td>Simon</td>
<td>40-50</td>
<td>Male</td>
<td>Bisexual</td>
<td>Sexual</td>
</tr>
<tr>
<td>Bill</td>
<td>30-40</td>
<td>Male</td>
<td>Gay</td>
<td>Sexual</td>
</tr>
<tr>
<td>Courtney</td>
<td>20-30</td>
<td>Female</td>
<td>Straight</td>
<td>Sexual</td>
</tr>
<tr>
<td>Princess</td>
<td>20-30</td>
<td>Female</td>
<td>Bisexual</td>
<td>Detention due to self-harm</td>
</tr>
</tbody>
</table>

Procedure

Ethical approval was obtained from the local NHS Research Ethics panel (Appendix G), while Research and Development approval was granted by the research site (Appendix H). Recruitment was undertaken by professional staff working within the research setting, with the aid of accessible information documents (see Appendices I and J). This ensured that the researcher was not privy to confidential information used to determine eligibility for participation, and potential participants did not experience undue pressure to participate. Capacity to consent was assessed in the first instance by the staff involved in recruitment, and revisited by the researcher prior to the interview taking place. Interviews were conducted in quiet rooms within the hospital environment. Staff were not present during interviews, to encourage participants to reflect accurately on interactions. However, hospital policy regarding observation meant that it was occasionally necessary for staff to remain outside the interview room. This was reflected on during analysis, to consider the impact this may have had on the participant’s perceived ability to speak openly.

Interviews

A semi-structured interview schedule or ‘topic guide’ was used to guide each interview (see Appendix K). Questions were constructed through supervision and reflection on the researchers’ clinical experience, and were designed to explore elements related to sex and relationships indicated by literature to be discussed in daily conversation. Questions explored conversations around sexuality,
value of relationships, marriage, risks related to sex, and formal procedures. This ensured some consistency between the interviews, while allowing discussions to be shaped by respondents’ experiences and interpretation of questions. Members of a local ID advocacy group provided guidance on importance of topics covered, and accessibility of language used. All questions aimed to be open-ended in nature, however this required varying levels of refinement during each interview, due to the participants’ idiosyncratic communication styles.

In contrast to Potter and Wetherell’s (1987) suggestion that interviews used for discourse analysis should be informed by an interventionist or confrontational interviewing style, the interviews in the current study were predominantly exploratory in nature. This was hoped to enable participants to reconstruct their experiences openly, without feeling challenged. It was felt this was especially important given the inherent power imbalance indicated by my position as researcher and ‘psychologist’, and other indicators of inequality such as wearing an alarm.

Transcription

Interviews were recorded and transcribed verbatim, including additional details of the conversation pertinent to CDA, such as interruptions, emphasis of words and hesitation (Oliver et al., 2005). Transcription did not begin until after the fourth interview, which allowed for reflection on the conversational phenomena considered valuable for analysis. For reasons of capacity and timeliness, all transcription was undertaken by an external transcriber (see Appendix L for instructions). The researcher listened back to the interviews to check accuracy and add further qualitative information as necessary, which allowed for complete immersion in the data in both auditory and transcribed formats.

Data analysis

CDA does not follow a specific set procedure, but specifies a number of assumptions to be borne in mind when analysing discursive data (van Dijk, 1993). It is concerned with understanding ‘talk in action’; that is, exploring the language used in social situations and considering the functions that use of particular discourses serve. CDA enables the researcher to explore not only participants’
experiences of staff interaction (as could be provided by IPA or other qualitative methodologies), but
to study the specific language used when reflecting on these interactions, and consider how the
language may serve to maintain the inherent power imbalance between staff and SUs (see Appendix
M for further methodological considerations).

To provide greater replicability, the analytic procedure was shaped by Potter and Wetherell’s
(1987) guidelines (see Appendices N, O and P for further detail). Each transcript was read repeatedly
to identify references to material relevant to the topic, and initial notes were made on potential
meaning and interpretation. For the first two transcripts, this was done by hand, with notes then
transferred into the software package NVivo (QSR International, 2012) to aid identification and
collation of similar sections and themes. Due to issues of timeliness, the remaining six transcripts
were coded directly in the software programme. Codes (‘nodes’) were ascribed to chunks of text, and
all transcripts were reviewed to establish whether examples of these codes were reflected in other
accounts. Particular attention was paid to instances where specific terminology was replicated across
multiple transcripts: while replication is not necessary for the theme to be meaningful in CDA,
consistency does indicate that participants are reflecting on a limited range of discourses within the
environment (Potter & Wetherell, 1987).

All resulting codes were transferred onto sticky notes so that they could be physically
grouped into themes. The resulting 11 themes were then organised into categories based on functions
of discourse. There were several iterations of the resulting categories and model, until the best fit was
found.

Throughout the analytic process, credibility checks were performed by the second researcher.
This enabled the author to consider alternative interpretations of the data, and enhance reflection on
the influences of their own position (Yardley, 2000). Member checks (assessing credibility of themes
with participants) were not carried out, due to the assumption in CDA that discursive themes are not
in speakers’ awareness (Elliot et al., 1999). The field researcher ensured that individuals were not
identifiable from the excerpts selected to illustrate the analysis, and verified resonance of themes with
his experience of the organisation.
Results

Eleven themes were identified (see Figure 1), relating to participants’ experience of discussions around sex and relationships with staff within the hospital. Three categories were constructed from the data analysis, which appeared to be closely linked in representing control over participants, while incorporating nuanced differences in the function of discourses and whose interests these served. The first category related to discourses which appeared to maintain the integrity and stability of the institution, while the second captured the specific discursive strategies used by staff, to maintain their position of power. A final category capture the dichotomised positions that participants appeared forced to adopt, in response to the controls imposed by the staff and wider institution.

Figure 2: Diagrammatic representation of categories and themes
Category 1 – Maintaining the ‘integrity’ of the institution

This category appeared to focus on restrictive practices by which participants were reminded of their subordinate position within the hospital, and the implications of such on discussion around sex and relationships. This was predominantly conveyed through restrictive discourses, which were dominant in the majority of participants’ accounts, and was both directly referenced, alongside appearing more subtly through the use of nuanced terminology.

Sex? “Can’t have it”

Interactions with staff were recounted as being heavily biased towards discussions of what participants “can and can’t do” (Mark, 623), including in relation to accessing social events (Simon, 227-230):

Simon: they ask me if I’m going and I say ‘Yeah, if I can’, and they come back and tell me you can go, or you can’t go, or it’s cancelled or not cancelled and stuff like that.

Mark recalled more explicit restrictions placed on interactions with others, speaking about a staff response to his relationship with his boyfriend (107-112):

Mark: [But we had] a lot of issues-

Interviewer: Right

Mark: =to do with (1) my sexuality, his sexuality,

Interviewer: [Right]

Mark: [with a member of staff]. Cause they said ‘you can’t hold hands, you can’t kiss’.  

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4 To aid the reader in identifying participant discourses, excerpts have been italicised throughout. As a result, elements of the transcription previously italicised to indicate quieter speech, have now been underlined.
He interpreted this restriction in the context of homophobic responses to gay relationships, however the restrictive discourse did not appear dependent on the sexuality of those involved, as Princess reflects in response to her boyfriend: (17-21):

*Interviewer:* So you said staff don’t help you here with relationships [with your partner?]

_Princess:* [They do and they don’t]. They don’t do it enough.

*Interviewer:* Okay so what do they do?

_Princess:* Not much (1) Just say yes and no if you can see em or not.

Use of restrictive terminology was hypothesised to ensure SUs remained in a position whereby permission was expected to be sought, and sometimes refused, dependent on the needs of the institution. In this regard, discussions were dominated by the notion of seeking and requiring permission to pursue romantic relationships.

“Allowed to hug once and that’s it” – conditional permission

Despite permission often being constructed in positive terms by participants, this indicated further restriction by the institution via the procedures through which this ‘conditional permission’ was granted. Princess spoke of being “allowed to hug once and that’s it” (282) while Courtney described the conditions placed on her when receiving visits from her boyfriend (140-147): “I’m allowed to kiss and cuddle him but anything else I’m not allowed to do”. Narratives of being ‘allowed’ served to further emphasise the dominance of the institution in determining the abilities and possibilities of those in the hospital.

Although this restriction could be constructed as hindering interpersonal intimacy and expression, consideration must be given to the wider socio-legal context influencing the hospital, and the associated responsibilities. The forensic nature of the hospital environment necessitates a certain level of restriction, to ensure the safety of both SUs and the public, with the medico-legal influence evident throughout many participant narratives.
“You should surely understand that it’s a hospital” – medico-legal discourse

The restriction placed on SUs regarding sex and relationships appeared often to be due to the function of the setting as a hospital. Mark recalls a conversation whereby staff asserted “you’re not in hospital to perform a relationship” (361), indicating restriction on the possibilities afforded service users due to the setting. This medico-legal discourse appeared also to influence participants’ construction of their own identity. For example Christian spoke of the reasons for his placement within the hospital: “it’s a PD unit personality disorder…. and that’s why I live here (.) I’ve got a learning disability and a personality disorder” (177-178). Similarly, Barry’s identity appears to be influenced by the context: when speaking of the difficulties of maintaining a relationship in hospital, he began by describing himself as “a person”, but corrected this to “a patient” (35), suggesting that his identity as a patient is foremost in the hospital.

In some instances, identifying the context as a hospital was presumed to confer joint understanding of the associated implications for SUs. Upon being asked to clarify her statement that “you can’t have sex in hospital” (7-8), Princess responded: “we::ll you should surely understand that it’s a hospital. You know that don’t you?” (68-69). It is possible that through institutional discourses constructing the environment as a hospital, certain personal and social expectations are activated, thus leading to pursuing particular courses of action over others.

Restrictive discourses in the forensic environment could be contextualised in relation to wider discourses around criminality and mental health. For example, Hall (2004) discusses the position of staff as powerful restrictors within such settings, and the ‘mentally ill’ in need of restriction due to perceived threat. The current participants, however, reflected discourses of threat not solely as perpetrators, but also potential victims. In this regard, the final theme in this category relates to the protective function of the hospital in supporting the rights and mental health of a vulnerable service user group.
“To protect us” – protective discourse

Themes of vulnerability and protection arose in relation to protection from discrimination by others, protection from abuse, and prevention of further offences which may necessitate legal sanction. When asked about staff discussions in relation to risk, Courtney reflected on her personal life experiences (325-330):

Courtney:  
One certain member of staff has to me. He’s warned me about (2) things (1) that could happen.

Interviewer:  
Okay. What sort of things has he said?

Courtney:  
Just be careful around the guy that I’m with cause he might hurt me.

Interviewer:  
Right. And has he said what- what you need to be careful of?

Courtney:  
Forcing me to do things. Cause of what happened in my past.

Courtney appeared to identify with the ‘victim’ position in the context of potentially sexually abusive relationships, while for others the ‘offender’ position also appeared to elicit a protective response from the institution. Bill described an interaction with staff whereby difficulties surrounding capacity to consent were broached (28-32):

Bill:  
They said ‘Well don’t be going near there’.

Interviewer:  
Okay. (3) What was their reason for saying ‘Don’t be going near there’?

Bill:  
Er.: because (1) they (2) didn’t understand (1) for the right and wrong.

Other participants similarly recalled conversations involving discourses of protection and risk. Princess opined that relationships should be able to proceed “if there’s no danger” (23), while Mark recalled a therapist’s concern over “what risks you could’ve put yourselves in” (221), due to the risk of getting “assaulted” (228) for displaying affection within a gay relationship. While serving a protective function, this could also be seen as relying on discourses of danger to control SUs’ intimate behaviour. As this was more apparent in regards to particular sexual identities, the belief systems and motivations of individual staff are therefore highlighted.
Category two – facilitating staff’s position of authority

The second main category encapsulated discourses which appeared to serve a function for staff, particularly representing different facets through which staff members are perceived to protect their authoritative stance.

“If there’s anything gone on then they’ll say it” – the when and where

This first theme is more procedural in nature, and relates to the context within which discussions around sex and relationships take place, if at all. Participants recalled little informal discussion of relationship issues, as Christian states: “they don’t talk about sexual relationships or nothing like that” (46), save for sometimes in a formal context: “do you have sexual relationships, yes or no” (59). This reliance on formal procedures for discussions around sex is commonplace across a number of transcripts. Simon reported the limited circumstances in which discussion around sex occurs: “if there’s anything gone on then they’ll say it... but if there’s nothing gone on then they won’t say anything” (505-507).

There was a difference in opinion about whether staff or SUs should take the lead in broaching discussions. Princess struggled to initiate discussions due to lacking confidence, and had found previous staff responses unhelpful: “they say something like that’s your responsibility not ours” (93-94), while Mark described his frustration at a therapist’s persistence in discussing his relationship: “it used to piss me off because he kept on bringing it up” (215-216). This indicates conflicting messages for staff regarding the importance of discussions about sex and relationships for SUs.

“Rules are rules” – rule talk

Commonplace amongst the majority of participant narratives was discussion of the hospital ‘rules’ about relationships and sex. This was predominantly in the context of whether sex or romantic relationships were allowed in the hospital, as explained by Princess (7): “you can’t have sex in hospital” and Sam (89): “cause it’s one of the, one of the rules (1) that we can’t have sex”. Reliance
on the ‘rules’ could remove responsibility for imposing restrictive decisions (e.g. preventing a SU visiting their partner) from the staff themselves and onto a wider structure, enabling staff to maintain a supportive relationship with SUs.

Rule talk was accepted to different degrees by different participants, and was sometimes constructed as being inconsistent “what you can do at the (club) and what you can do on the wards is two different things” (Simon, 411-412) or inaccurate: “so they say if you kiss or:: hug, it’s breaking the hospital rules when it isn’t” (Mark, 583-584). This appeared to be partly due to a lack of understanding about the rationale for certain rules.

“I don’t know they won’t tell you” - withholding understanding

The level of understanding of the participants in relation to the rules varied to some extent, but was mostly limited. For example Courtney shared the lack of explanation from staff regarding contact with her boyfriend (145-152):

Interviewer: And what have they said the reasons for that are?
Courtney: They just said inappropriate contact, they just said.
Interviewer: Inappropriate contact? Okay. What-what do they mean by that?
Courtney: (2) Dunno.

Similarly, Mark described difficulties in expressing gender identity through choice of clothing, and the response from staff to prevent this (491-497):

Mark: They say ‘you can’t come out your bedroom in drag’.
Interviewer: Why do they say that?
Mark: Because they say it’s not allowed. (2) Erm, of course it is, it’s how=
Interviewer: =Why’s it not allowed?
Mark: I don’t know they won’t tell you

van Dijk (2008) describes the discursive strategy of withholding knowledge from subjugated groups to maintain a powerless position. This appeared to be particularly relevant here, as withholding adequate explanation of the rules ensured SUs were not able to challenge the staff position.
Alongside the use of rule talk to limit sexual identity and expression, participants also referenced the imposition of staff wishes and perspectives. Bill described the response from staff when seeking support to maintain his relationship with another service user (181-185):

Bill: Er (.), they said ‘what’s the point in having a boyfriend in this place?’

Interviewer: They said what, ‘What’s the point of having a boyfriend?’ =

Bill: =Yeah.

Interviewer: What do you think they meant by that?

Bill: Because (2) because I can’t have sex with him or anything.

This view that relationships are futile without sex has far-reaching consequences for the possibility of romance, in an environment where sex is prohibited. Aside from the restrictions placed on sexual contact, other aspects of normative romantic relationships were also challenged by personal staff perspectives, as Courtney recalls (202): “he said that you shouldn’t be getting married because you’re too young”.

For some, restriction on contact in relationships was perceived as being due to discrimination. Mark stated that “some staff are homophobic” (118), recalling their reluctance to support his sexual expression: “one of the staff said ‘God made Adam and Eve, not Adam and Steve’” (34-35). This suggests that staff are drawing on discriminatory discourses to challenge the validity of an individual’s sexual identity, if it is inconsistent with their own views.

“Just sat there, with a face on” – actions speak louder than words

In some cases the disclosure of messages around sexuality was not solely in terms of what SUs heard but, through silence and action, what they saw and experienced. For example Bill, Princess and Mark all spoke of relationships coming to an end due to one party being ‘moved’, with no consideration for how the relationship would be maintained:
Interviewer: =have you had any::, any sort of– have you had a boyfriend while you’ve been here?

Bill: Yeah.

Interviewer: Great. How long did that relationship last?

Bill: Er::: a year.

Interviewer: Oh okay. What-

Bill: He moved.

(Bill, 162-170)

In contrast to the accepted importance of romantic relationships in non-disabled society, the ignorance of romantic ties when considering residential placements seems to provide strong messages regarding the importance and credibility of SUs’ relationships.

Perspectives regarding the quality of relationships were also shared non-verbally, as Courtney recalls when supported to attend a LGBT social group (412-423):

Interviewer: What sort of things did they say that gave you that idea?

Courtney: Well they didn’t- just didn’t join in or anything.

Interviewer: Oh.

Courtney: They just sat there

Interviewer: Right

Courtney: With a face on.

Interviewer: With a face on?

Courtney: Yeah.

Interviewer: What sort of face?

Courtney: (. ) Sad face.

Interviewer: Oh.

Courtney: (2) So they mustn’t have agreed with like (. ) gay people things like that.

Again, the non-verbal messages of disagreement with a particular sexual orientation serve to reinforce a disempowered position whereby SUs’ identity and choices must be validated by the authority of staff.
Category three – acceptance and resistance talk

Although not originally a focus of the research, an important category of themes emerged regarding participants’ responses to the messages received from staff. Predominantly dichotomised into one of two approaches, respondents described how they would either adhere to rules and instructions from staff, which appeared to become internalised in their narratives, or rebel through both functional, and dysfunctional, methods.

“You can’t hold down a relationship” – passive acceptance

Some participants reported agreeing with the messages given by staff, particularly those perceived as ‘advice’ and thought to be in SUs’ best interests. For example, Courtney spoke of being prevented from visiting her boyfriend due to staff worries that she would become “unsteady” when having to return to the hospital, a sentiment with which she agreed (115-121).

Staff messages around the possibility and importance of maintaining a relationship while in the hospital also appeared to shape participants’ choices. Barry stated that: “If you’re stuck in these places you can’t, you can’t hold down a relationship” (32-33), indicating an acceptance of the restricted life opportunities while in the hospital.

“Ain’t gonna stop us” - active resistance

While the subordinate position was accepted by some participants, resistance was demonstrated by others. The extent of, and mechanisms by which participants sought to regain control over their relational experiences was partially influenced by their self-positioning in relation to staff and other SUs. Mark identified himself as “one of the outspoken clients” (85), which was reflected in assertion of his experience and use of litigious discourse. Mark described tackling the institutional influences head on (140-142): “So I’ve rung up the solicitors (.) and we’re that close, very close to sending HOSPITAL to court (.) under the:: Human Rights act”. His reliance on legal discourse was apparent throughout the interview, through references to local policy, and wider political and legal approaches to SU support.
Pursuing formal grievance procedures was not always considered an option, and sometimes the much-sought affection and intimacy of relationships was pursued in a covert and defiant manner:

Mark: =When you’re in hospital, you’re in hospital for quite a long time (1) erm (1)

and they expect you to (1) not have sex. (2) Conversation would be ‘ain’t
gonna stop us’. Er, because we’ve still got needs. (234-237)

Similarly, Courtney described the difficulty in spending time with a partner due to institutional restrictions on being allowed in each other’s rooms: “but I barricaded us in” (311), also reflecting on the decision to engage in sexual activity despite the repercussions from staff: “I just get myself into trouble” (156).

Overall, participants’ responses place themselves in a controlled or rebellious position, both identifying with the subjugated pole of the power dynamic.
Discussion

This study aimed to explore the conversations held between staff and SUs in a secure setting for individuals with ID. Participant narratives appeared to indicate three main categories of discourse prevalent within the hospital: the first appeared to maintain the integrity and function of the institution; a secure hospital for individuals detained for the protection of themselves and the public. The second category focussed on discourses enabling staff to maintain an authoritative position, from which views contradicting the prevalent ideology could be controlled. A third category focussed on participants’ responses to control from staff and the institution.

Research into organisational discourse positions speakers (in this case both participants and staff) not merely as representing the institution through discourse, but as social actors serving to maintain the organisation structure (Mumby & Mease, 2011). Discourses around sex in the hospital appeared to differ somewhat from the wider ideology around sex and relationships for people with ID, something also found by Grieve et al. (2009), potentially due to staff struggling to determine the appropriateness of intimate relationships (Bane et al., 2012). The role of the institution as a protective force was borne out in participant narratives, mirroring Winges-Yanez’s (2013) finding that staff often place themselves as protectors of people with ID, without realising the paternalistic nature of the role, and the implications for SUs’ rights.

The restrictive discourse, and limitations on intimate relationship opportunities, has also been replicated in other studies. Fish (in press) explored the sexual experiences of females residing in the same hospital as the current study, through both SU and staff accounts. One staff member stated “they’re just told that relationships are not allowed” (p.8), while SUs recalled being unsure as to what behaviour was ‘allowed’ in the context of sexual relationships. This uncertainty reflects the theme of ‘withholding understanding’ in the current study, which could be explained in part by a lack of clarity in staff themselves, creating an inability to provide comprehensible guidelines. Both SUs and staff could be supported to better understand the rules, and reasons for these, with the help of accessible policy documents provided by the hospital.

While the study was predominantly concerned with spoken discourse, non-verbal indications of staff views were considered equally important in conveying messages around sex and relationships.
Participants reflected on non-verbal indicators of staff discomfort with certain aspects of relationships, something that is particularly important for staff to consider given the reliance on body language to aid interaction for people with ID (e.g. Bradshaw, 2001; Caldwell, 2014).

Alongside the impact of body language, Ward and Winstanley (2003) highlight the importance of silence in discourse. They suggest that things that “remain unsaid” (p.1260) provide messages equally as powerful as spoken word. The lack of discussion around sex outside of formal avenues provides powerful messages around the acceptability of sex talk, and could perhaps be explained by staff members’ perception of their ability to navigate such discussions. Evans et al. (2009) explored staff attitudes towards sex in ID services, and found staff lacking in confidence to discuss sex or relationships with SUs. Healy et al.’s (2009) study with SUs in the same context revealed a perception that staff were “afraid to talk about it” (p.909), indicating an awareness of staff skills and limitations, and the impact on service user quality of life. This lack of confidence could result in staff simply replicating the existing ideology around sex, irrespective of their own views, perhaps explaining the dissonance within the literature between staff attitudes and SU experiences. This suggests that change at the staff level would also require significant organisational change, including robust training and increased staff support, so that they feel able to engage in discussions around sex.

The current study emphasised the impact of the forensic context on staff and SU discourses. This is not, however, restricted solely to forensic services, as Hollomotz’s (2009) exploration of attitudes in residential ID services found: similar themes of danger and protection were dominant, with sexual relationships deemed ‘unsafe’ by staff. There has been a tendency within the literature to focus on the protection and vulnerability of SUs, rather than promoting choice (Fish, in press), which is in contrast to the Valuing People Now (DoH, 2009) policy prioritising relationship planning and support for people with ID.

Clinical implications and recommendations

The category of service user responses to control is particularly important when considering implications for clinical practice, and future offending trajectories. The Counterfeit Deviance Hypothesis of sexual offending by individuals with ID suggests that deviant sexual arousal and
behaviour is influenced by limited opportunities for functional intimate relationships (e.g. Griffiths et al., 2013). In light of this, the theme of ‘active resistance’ suggests that the lack of opportunities to pursue relationships within the hospital may be exacerbating the likelihood of covert sexual activity, potentially offensive, taking place. Similarly, Mark’s assertion that he is “not in hospital to perform a relationship” brings into question the role of the institution in providing treatment to prevent further offending. The ‘Good Lives’ model (Ward et al., 2007) emphasises the importance of developing functional relationships, platonic and intimate, to act to desist sexual offending. Staff facilitation and support of relationships within the hospital setting could, therefore, complement existing therapeutic strategies to tackle future offending.

The level of staff control over intimate relationships also raises questions of responsibility for offending behaviour. Participants reflected on perceived inability to control sexual urges, inferred by constant staff presence, which draws on conservative views of ID sexuality (Cuskelly & Gilmore, 2007). Acceptance of responsibility is a key aspect of sex offender treatment (Ware & Mann, 2012), an important consideration in light of the forensic histories of the participants. If staff take responsibility for prevention of sexual contact through external management, this implies the need for continuous external management within the community, and could remove the opportunity for SUs to develop their own internal inhibitors, with perhaps negative implications for future offending (e.g. Finkelhor, 1984). Given the changes underway due to the Transforming Care (2015) agenda, it is likely that staff support will be reduced once secure beds are reduced, and care is provided in the community (as per the corresponding levels of procedural and relational security in secure and community environments [e.g. Kennedy, 2002]). This therefore raises concerns that, with reduced staff monitoring and management of risk, the likelihood of SUs committing further sexual offences may increase.

Interestingly, despite the secure environment, and the prevalence of sexual offences within participants’ histories, there was little mention of risk assessment by participants. This perhaps implies that collaborative discussions around sexual risk do not take place. Undertaking joint risk assessments (e.g. ARMIDILO-S, Boer et al., 2004) could facilitate constructive discussion around risk
and sexual behaviour, thereby improving SUs awareness of their own risk factors, in turn improving an ability to monitor and manage their own risk.

Staff values and attitudes are also an important consideration in light of the current findings. Restrictive or discriminatory attitudes are potentially damaging in an environment where prevalent cultural discourses are the foundation for developing sexual identity (Horowitz & Newcomb, 2002). Employing a values-based recruitment strategy (e.g. Health Education England, 2014) may enable prospective staff to be selected on the basis of promoting the rights and choices of people with ID, while ensuring restrictive or disempowering views do not become integrated into the service culture. Providing staff training informed by the Human Rights Act (1998), particularly the right to private and family life (Article 8), may also facilitate a more balanced consideration of the importance of relationships, and assist in improving quality of life.

It is important to consider the context of the service, and the impact that a negative or restrictive environment will have on individuals’ quality of life. Alongside being a secure service, the hospital is the home of many vulnerable and already disempowered individuals. As such, further efforts should be made to provide a supportive and inclusive environment, within which safe and meaningful relationships can be developed (DoH, 2009).

The prohibiting of sexual relationships within hospital settings remains a contentious topic. Hospital policy allows masturbation in private areas, specifically bedrooms, suggesting that if such spaces are private for the purposes of masturbation, then they could also be deemed private for other sexual interactions. A minority of community services follow this rationale, with appropriate safeguarding precautions and considerations regarding capacity to consent. As one contributor to Hollomotz’s (2009) study shares, the policy in their group home allows partners to stay in SUs’ bedrooms overnight, with an alarm button installed for emergencies. The incorporation of similar policy within the research setting would, however, involve consideration of the forensic nature of the setting, and require considerable change to the ethos and staffing procedures within the hospital.

Contextual considerations and limitations

Throughout the research process I was aware of my preconceptions, particularly an expectation that data may reflect somewhat restrictive terminology being used. Although no study is
completely free from bias, supervisory discussion of transcripts and themes enabled consideration of multiple perspectives, providing enhanced credibility to findings, and reflection on my own position regarding the data.

I was mindful of how I could be positioned by participants, in relation to their experiences within the hospital. Wearing an alarm and identification, I may have been viewed as part of the staff, or authority, thereby impacting on participants’ ability to speak openly without fear of judgement or repercussion. The very nature of the ‘interview’ may also have impacted on participant disclosure, and one potential participant withdrew due to fear of how the recording would be used. This can be understood in the context of previous experience (e.g. police interviews), although it is unavoidable in order to maintain data accuracy. This potential anxiety around the consequences of speech was evident in how much participants felt able to say. As can be seen from the differences in participants’ representation in the results, some interviews were considerably shorter than others, resulting in a quieter voice in the analysis. It would be important to explore methods by which potential participants can be reassured their safety should they engage in research, to facilitate the most honest and forthcoming accounts possible.

It is also important to note the demographic information provided by participants, and the dominance of those identifying as non-heterosexual. It is possible that, of those approached to take part, individuals identifying as non-heterosexual may have experienced more strained interactions with staff, and may feel more strongly about being heard. Those accessing the LGBT social group within the hospital may also have felt more comfortable speaking out, thereby more likely to agree to participate. The prevalence of sexual offending in participants’ histories may also have influenced the discourses they are privy to. As such, the themes discussed above are unlikely capture the full range of discursive strategies used by staff within the hospital, yet the repetition of discourses across participant accounts indicates a relatively limited set of interpretative repertoires on which to draw (Potter & Wetherell, 1987).
Future research

The current study explores the discourses as perceived by service users within one institution as reflected by eight participants, and therefore is not aimed to be generalisable to other services. As such, future research could explore the possibility that similar discourses may shape other secure services for people with ID. It may be probative to focus on non-forensic ID environments, to consider the impact of the forensic context. Outcome studies could also examine the effectiveness of staff training in promoting SU choice around sex and relationships, or investigate the impact of introducing values-based recruitment into services.
References


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how this is maintained through social relations. *Disability and Society*, 29(9), 1473-1485.


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Appendices

Within this final chapter is presented supplementary detail which is designed to add context, depth and clarity to the preceding thesis. Confirmation of ethical and research site approval demonstrates that the researcher adhered to ethical and departmental guidance regarding research conduct, and an extended reflexive statement allows the reader to situate the research in relation to the author’s interests and experiences, while developing a deeper understanding of the factors influencing the research procedure. Excerpts from coded transcripts can be found, alongside examples of the author’s reflections throughout the analytic process, offering clarity around both the content and procedural aspects of data analysis. Finally, an accessible version of the empirical paper created for the participants and wider users of the research site, is included.
Appendix A

Search terms and limiters for systematic review

<table>
<thead>
<tr>
<th>Search</th>
<th>Term</th>
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<tbody>
<tr>
<td>1</td>
<td>&quot;learning disab*&quot; OR &quot;Intellectual Disab*&quot; OR &quot;mental* Retard*&quot; OR &quot;developmental* Disab*&quot; OR &quot;intellectual* impair*&quot; OR &quot;mental* handicap*&quot;</td>
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<td>AND</td>
<td>&quot;sexually inappropriate behaviour&quot; OR &quot;sexual devian*&quot; OR &quot;sex* offen*&quot; OR paedophil* OR &quot;sex* abus*&quot; OR paraphilia OR “inappropriate sexual behaviour”</td>
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<td>AND</td>
<td>staff OR carer* OR professional*</td>
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<td>AND</td>
<td>Attitude* OR perce* OR attribut* OR experience* OR narrative* OR view* OR expla* OR interview*</td>
</tr>
</tbody>
</table>

**Limiters**

Source type: Academic journals, dissertations/theses and reviews only

Date: between year 2000 and present day

English language only

Databases: Scopus

CINAHL PLUS

PsycINFO

British Library EThoS

Science Direct

Medline
Appendix B

Critical Appraisal Skills Programme checklist for qualitative research

10 questions to help you make sense of qualitative research

How to use this appraisal tool

Three broad issues need to be considered when appraising the report of a qualitative research:

- Are the results of the review valid?
- What are the results?
- Will the results help locally?

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions.

There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

There will not be time in the small groups to answer them all in detail!

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Screening Questions

1. Was there a clear statement of the aims of the research?
   □ Yes  □ Can't tell  □ No
   HINT: Consider
   • What was the goal of the research?
   • Why it was thought important?
   • Its relevance

---

2. Is a qualitative methodology appropriate?
   □ Yes  □ Can’t tell  □ No
   HINT: Consider
   • If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
   • Is qualitative research the right methodology for addressing the research goal?

Is it worth continuing?
Detailed questions

3. Was the research design appropriate to address the aims of the research? □ Yes □ Can't tell □ No

HINT: Consider
- If the researcher has justified the research design (e.g., have they discussed how they decided which method to use)?

4. Was the recruitment strategy appropriate to the aims of the research? □ Yes □ Can't tell □ No

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g., why some people chose not to take part)
5. Was the data collected in a way that addressed the research issue?  
☐ Yes  ☐ Can’t tell  ☐ No

HINT: Consider
- If the setting for data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?
- If methods were modified during the study. If so, has the researcher explained how and why?
- If the form of data is clear (e.g. tape recordings, video material, notes etc)
- If the researcher has discussed saturation of data

6. Has the relationship between researcher and participants been adequately considered?  
☐ Yes  ☐ Can’t tell  ☐ No

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during
  (a) Formulation of the research questions
  (b) Data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design
7. Have ethical issues been taken into consideration?  
   - Yes  
   - Can't tell  
   - No  

HINT: Consider
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained.
- If the researcher has discussed issues raised by the study (e.g., issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study).
- If approval has been sought from the ethics committee.

8. Was the data analysis sufficiently rigorous?  
   - Yes  
   - Can't tell  
   - No  

HINT: Consider
- If there is an in-depth description of the analysis process.
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process.
- If sufficient data are presented to support the findings.
- To what extent contradictory data are taken into account.
- Whether the researcher critically examined their own role, potential bias, and influence during analysis and selection of data for presentation.
9. Is there a clear statement of findings?

HINT: Consider

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researchers arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy?, or relevant research-based literature?
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used
Appendix C

Newcastle-Ottawa Scale adapted for cross-sectional studies

**Newcastle-Ottawa Scale adapted for cross-sectional studies**

**Selection:** (Maximum 5 stars)

1) Representativeness of the sample:
   a) Truly representative of the average in the target population. * (all subjects or random sampling)
   b) Somewhat representative of the average in the target population. * (non-random sampling)
   c) Selected group of users.
   d) No description of the sampling strategy.

2) Sample size:
   a) Justified and satisfactory. *
   b) Not justified.

3) Non-respondents:
   a) Comparability between respondents and non-respondents characteristics is established, and the response rate is satisfactory. *
   b) The response rate is unsatisfactory, or the comparability between respondents and non-respondents is unsatisfactory.
   c) No description of the response rate or the characteristics of the responders and the non-responders.

4) Ascertainment of the exposure (risk factor):
   a) Validated measurement tool. **
   b) Non-validated measurement tool, but the tool is available or described.*
   c) No description of the measurement tool.

**Comparability:** (Maximum 2 stars)
1) The subjects in different outcome groups are comparable, based on the study design or analysis. Confounding factors are controlled.
   
a) The study controls for the most important factor (select one). *

b) The study controls for any additional factor. *

**Outcome:** (Maximum 3 stars)

1) Assessment of the outcome:
   
a) Independent blind assessment. **

b) Record linkage. **

c) Self report. *

d) No description.

2) Statistical test:
   
a) The statistical test used to analyze the data is clearly described and appropriate, and the measurement of the association is presented, including confidence intervals and the probability level (p value). *

b) The statistical test is not appropriate, not described or incomplete.

This scale has been adapted from the Newcastle-Ottawa Quality Assessment Scale for cohort studies to perform a quality assessment of cross-sectional studies for the systematic review, “Are Healthcare Workers’ Intentions to Vaccinate Related to their Knowledge, Beliefs and Attitudes? A Systematic Review”.

We have not selected one factor that is the most important for comparability, because the variables are not the same in each study. Thus, the principal factor should be identified for each study.

In our scale, we have specifically assigned one star for self-reported outcomes, because our study measures the intention to vaccinate. Two stars are given to the studies that assess the outcome with independent blind observers or with vaccination records, because these methods measure the practice of vaccination, which is the result of true intention.
Appendix D

Author guidelines on preparation of papers for JARID.

5. Manuscript types accepted

Articles should not exceed 7000 words. Brief reports should not exceed 2000 words.

6.1 Format

**Language:** The language of publication is English. Authors for whom English is a second language must have their manuscript professionally edited by an English speaking person before submission to make sure the English is of high quality. It is preferred that manuscripts are professionally edited. A list of independent suppliers of editing services can be found at [http://authorservices.wiley.com/bauthor/english_language.asp](http://authorservices.wiley.com/bauthor/english_language.asp). All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

6.2 Structure

All manuscripts submitted to the *Journal of Applied Research in Intellectual Disabilities* should include:

- **Cover Page:** A cover page should contain only the title, thereby facilitating anonymous reviewing. The authors’ details should be supplied on a separate page and the author for correspondence should be identified clearly, along with full contact details, including e-mail address.

- **Running Title:** A short title of not more than fifty characters, including spaces, should be provided.

- **Keywords:** Up to six key words to aid indexing should also be provided.

- **Main Text:** All papers should have a structured abstract (maximum 150 words) as follows: Background, Method, Results, and Conclusions. The abstract should provide an outline of the research questions, the design, essential findings and main conclusions of the study. Authors should make use of headings within the main paper as follows: Introduction, Method, Results and Discussion. Subheadings can be used as appropriate. All authors must clearly state their research questions, aims or hypotheses clearly at the end of the Introduction. Figures and Tables should be submitted as a separate file.

- **Style:** Manuscripts should be formatted with a wide margin and double spaced. Include all parts of the text of the paper in a single file, but do not embed figures. Please note the following points which will help us to process your manuscript successfully:
  - Include all figure legends, and tables with their legends if available.
  - Do not use the carriage return (enter) at the end of lines within a paragraph.
  - Turn the hyphenation option off.
  - In the cover email, specify any special characters used to represent non-keyboard characters.
  - Take care not to use l (ell) for 1 (one), O (capital o) for 0 (zero) or ß (German esszett) for (beta).
  - Use a tab, not spaces, to separate data points in tables.
  - If you use a table editor function, ensure that each data point is contained within a unique cell, i.e. do not use carriage returns within cells.

Spelling should conform to *The Concise Oxford Dictionary of Current English* and units of measurements, symbols and abbreviations with those in *Units, Symbols and Abbreviations* (1977)
6.3 References

The reference list should be in alphabetic order thus:

Journal titles should be in full. References in text with more than two authors should be abbreviated to (Brown *et al*. 1977). Authors are responsible for the accuracy of their references.

NB: although the author guidelines request Tables to be submitted separately, for the purposes of academic thesis submission University guidelines will be followed. Journal submission will follow the requested formatting.
Appendix E

Email communication from the editor of JARID clarifying required referencing style.

Peter Langdon [P.E.Langdon@kent.ac.uk]
29 January 2016 09:07

Dear Nici,

The journal style is detailed within the instructions to authors, which is found below. You can download either the endnote or refman style files, or manually insert your references following the examples (which again are found below). APA style is for APA journals. Wiley tends to use Harvard or Vancouver, and we use Harvard.

b/w Peter
Appendix F

Reflexive statement

Interest in the area

My interest in the current research area was first piqued during my own time spent as a carer supporting young people with ID in a locked setting. While keen to facilitate ‘normal’ developmental and social experiences (as far as was practicable) for the young people in my care, I was informed that it was “inappropriate” to discuss sex, relationships or sexuality with service users. Relationships were prohibited within the establishment due to its hospital status, and the nature of detention under the MHA meant that most service users were unable to seek social or sexual relationships outside of the establishment. I was concerned as to how these individuals, with existing cognitive, emotional and interpersonal difficulties, were to develop as social individuals without such opportunities.

Throughout other practitioner roles, and including within my placements as a Trainee Clinical Psychologist, concerns around ‘inappropriate’ sexual expression, predominantly reflecting the restrictive views of staff, were frequent causes of referral for psychological support. My interest in forensic work and risk assessment led me to experiencing the issues surrounding sexuality in ID from multiple perspectives: although a proportion of difficulties involved deviant or abusive behaviour, a number also appeared to be unfortunate consequences of a lack of opportunities to engage in appropriate interpersonal interactions. For example, support was sought for a young man masturbating on public transport, due to being prohibited from doing so at home. I continued to question the messages around sex and relationships that are conveyed to individuals with ID, and the implications these have for a lifestyle already restricted by society’s expectations.

Methodological decision-making

I chose to utilise a qualitative methodology within the current study for a number of reasons. Firstly, I believe that quantitative methods, while useful for quantifying aspects of experience and perspective, do not capture the entire essence of experience. Quantitative research is able to offer a perspective on the ‘what’, yet it is the qualitative methodology which allows us to consider experiences in greater depth, and begin to understand the ‘why’.
My second reason was to provide a voice for a group who are already marginalised by their inherent differences and difficulties due to being diagnosed with ID. This is then compounded by science and society’s historic lack of emphasis on understanding the experiences of those with ID, particularly in relation to social equality (for a more in-depth discussion see Coons and Watson, 2013), when perhaps they hold the most important voices to be heard.

Thirdly, my beliefs about the nature of what information we are to seek, and how we approach exploring others’ experiences, indicate that a qualitative methodology is required to appreciate both individual, and collective, perceptions of social actions. I would tend to position myself as a critical realist, believing that there is some certainty about the world that exists independently of how we perceive and experience it, often known as ontological realism, while our understandings of events, constructs and interactions tend to be shaped predominantly by individual and social ideologies (social constructionism). I would not say that I am epistemologically a pure social constructionist, as I believe that there are individual belief systems that influence dialogue within social interactions, rather than events being solely created through discourse. Teun van Dijk (2002) eloquently describes this as a sociocognitive approach, combining representations within the mind, with those created in society and through discourse.

My personal view of the construct of ID is shaped by my epistemological understanding: criteria for diagnosis, and psychometric measurement of objective ‘intelligence’, allow identification of areas of support required, and access to services that are able to provide this support. The nuances of the associated difficulties, however, are often incorrectly inferred by others, in essence further disabling the individual by supposing a lack of ability, or interest, to pursue various life opportunities (e.g. driving, holding down a job and pursuing sexual or romantic relationships). My experiences of ID and locked settings, and the staff working there, have often fallen within this more restrictive interpretation of the construct of ID. Often this has been due to a lack of understanding, with staff relying on socially constructed interpretations of relevant difficulties and strengths, inadvertently further restricting their service users’ life experiences. This is often demonstrated in regards to the relationships pursued by individuals with ID, and the difficulties they may face in this regard. In my experience, the topics of relationships and sex are only broached when proving to be a problem, in
stark contrast to the emphasis placed on interpersonal functioning apparent in many other platonic and professional interactions.

My views on sexual orientation may also be worth sharing here. I believe that sexuality can be dynamic and fluid, and sometimes confusing. Sexuality is often viewed as a private and personal construct, however my understanding of this is the result of decades of social pressure and stigma around disclosing sexuality that may not be approved by certain factions of society. Sexuality can define a significant aspect of an individual’s identity, and as such can be a source of both distress, and pleasure. In relation to individuals with ID, sexual orientation is often presumed by those who support them, and is usually restricted to a heterosexual relationship with one other partner. I felt it important in the current study to ask about sexual orientation, both to allude to an environment in which discourse around sexuality is safe, and to better understand the contextual influences on staff-service user interactions.

It may also be beneficial to share my perspective on the forensic environment and its inherent restrictions at this point. While consideration of legal culpability and the complexities of the legal system are outside the scope of this discussion, forensic services for individuals with ID are primarily an environment to facilitate assessment and intervention for mental health difficulties related to the commission of offenses. I believe it is important that such settings are able to provide a boundaried environment that can promote the safety of both the clients, and the public, while practicing in a way that maintains the rights and dignity of individuals

Implications of my experiences on analysis

As with all qualitative methodology, the researcher brings their own understandings and experiences into data analysis. In terms of my own understandings, my current role as a Trainee Clinical Psychologist is likely to enhance my receptiveness to messages regarding emotional well-being, while interest in forensic issues will draw attention to risk-related discourse. The experiences outlined above in relation to sexual and relational inequality afforded to adults with ID in care services, alongside my selection of a methodology concerned with identifying mechanisms by which power imbalances are created and sustains, presupposes that I expect potentially restrictive or dominating discourses to become apparent in service users’ experiences. That said, I will, of course,
strive to be guided predominantly by the data itself, while being reflexive in my analytic approach so as to bear in mind and minimise the possibility for personal biases to emerge through the analysis process (Yardley, 2000).

References


Appendix K

Interview schedule/topic guide

Interview schedule / subject list

NB this is subject to alteration following service user consultation

Demographics
Age
Gender
Pathway / index offense category
Sexual orientation

Questions
Where do you live?
How long have you been here? What is it like?
Tell me how you get on with the people you live with?
What does the word relationship mean to you?
Are you in a relationship with somebody?

Possibly create relationship donut

What have staff said about why you live at HOSPITAL?
Why do you think you are living here? Why is that different?
Do you ever wonder what staff think about relationships?
What do staff say about service users having relationships?
Have you spoken to staff about sex?
What is it like talking to staff about sex or relationships? How does it feel?
What do staff say about service users having sex?
What do staff say to each other about sex?
What do staff say about sex in meetings? Is this different to how they talk on the ward?
What do staff say about the risks about having sex?
What do staff think about service users getting married?
What do staff think about people who are gay?
Appendix L

Discourse analysis transcription details provided for transcriber

**Discourse analysis transcription**

Discourse analysis transcription varies dependent on what elements of the conversation are felt to be useful/helpful. I have outlined the aspects that I feel are important for my project.

It is important to have the words transcribed verbatim, including all interruptions, speakers talking over each other etc. There are some ways this can be done, it may be easiest to show this using [ ] to show where the speech overlaps.

<table>
<thead>
<tr>
<th>Interviewer:</th>
<th>So tell me why [you feel that way?]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respondent:</td>
<td>[because of] blah blah.....</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Interviewer:</th>
<th>We will be using this Dictaphone[</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respondent:</td>
<td>[yeah]</td>
</tr>
<tr>
<td>Interviewer:</td>
<td>to] record etc.</td>
</tr>
</tbody>
</table>

If speakers continue on straight from each other, = signs can show this:

<table>
<thead>
<tr>
<th>Interviewer:</th>
<th>Sure, so that was hard=</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respondent:</td>
<td>=Yes very</td>
</tr>
</tbody>
</table>

If someone begins talking, and then cuts off without being interrupted, e.g. to correct themselves, this could be shown as:

| Interviewer: | you were telling me that you were happie- more comfortable when.... |

For my research it is also important to note any times when the speech may be emphasised (louder), and you could put this in **bold**. If words or parts of the speech are whispered or quieter, show this in *italics*.

| Respondent:  | she didn’t like it **that** much, it was more of a **fling**. |

Pauses in the speech, and their approximate length, can be shown by:

- (.) for short pauses (up to 1/10 second; not measurable)
- (0.5) for around half a second
- (2) for 2 seconds etc

Long out-breaths (like a sigh) can be shown as hhh, or sharp in-takes as .hhh

A colon can show the elongation of the preceding syllable or sound, e.g. “Y::eah sort of like that”.

If there are parts of the speech that are unintelligible, just put (unclear). Or if you want to have a guess at what it says put this in brackets with a question mark, e.g. (hospital?) etc.
Coding taken from guidance in:


Appendix M

Methodological considerations

<table>
<thead>
<tr>
<th>Approach</th>
<th>Positives</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grounded theory</td>
<td>Able to develop understanding of new constructs from participant info</td>
<td>Not looking to test a model, but focus on experiences</td>
</tr>
<tr>
<td>Interpretative phenomenological analysis</td>
<td>Understand P’s experiences and interpretation and meaning given to these</td>
<td>Not looking for homogenous group, more emphasis on variety of narratives and specific language</td>
</tr>
<tr>
<td>Thematic analysis</td>
<td>Coherent and clear structure, would provide model of themes</td>
<td>Seeking deeper understanding of data and getting underneath the themes to discourse and meaning</td>
</tr>
<tr>
<td>Narrative analysis</td>
<td>Provides reflection on participant stories, experiences and identity.</td>
<td>Would not add to the evidence base, focus on discourse and interaction which would not be captured.</td>
</tr>
<tr>
<td>Critical discourse analysis</td>
<td>Enables consideration of power, focus on specific language used and infer function</td>
<td>Not focussed procedure, rather set of principles</td>
</tr>
</tbody>
</table>
Appendix N

Example coded transcription depicting initial coding
Appendix O

Flow chart demonstrating coding and analytic process
Appendix P

Excerpt from reflective journal

Courtney 29/1/16

word

Staff written in wrong way so Courtney was still in bed; staff member
displeased at me asking her to see if Courtney would get out of bed, rather
waltzful. She appeared tired, voice got quieter when handed the
discourse on it & put her hand over her mouth.

Seemed ok to talk about some things, but couldn’t elaborate on a
number of questions. “Inappropriate” relationship? How
accurate are accounts? “I wasn’t very happy,” said last not to get
back with partner, was read? Staff member seemed to be more
deriving of boundaries? Seeks to hide behind “inappropriate” label
then maintain appropriate yet inappropriate boundaries?

Staff role as advising & supporting.
Risk of safety disposal or protection? Not able to visit boyfriend as
may get upset…?

No staff member – discussing & sexuality – blamed/interpreted
by SN? Avoiding after ten modulating opp. relationship (SPD)
Categorized by office history “in my past”
Engaged – getting married? Staff – too young?

After intense, strange being recorded last “as we’re used to it” not
mimicking body language.
Getting “giddy” – caused staff word?

Trust again. SN choice because don’t want staff reporting/spreading