Investigating staff's attitudes and willingness to support men and women with mild intellectual disabilities on matters relating to their sexuality

&

Clinical Research Portfolio

Volume I

(Volume II bound separately)

Andrea Gallagher

July 2011

Submitted in part fulfilment of the requirements for the Degree of

Doctorate in Clinical Psychology (D. Clin. Psy.)

Faculty of Medicine Graduate School

"Declaration of Originality Form"

You have a responsibility to the University, the Faculty, your classmates, and most of all to yourself, to act with integrity in your academic work. In particular, the work that you submit for assessment, other than for team exercises, *must be your own.* Just as cheating in examinations is a serious offence, so any form of collusion or plagiarism in assessed exercises is dishonest and unacceptable to the University.

The following is an extract from the University's Statement on Plagiarism. Please read it carefully and sign the declaration below.

Plagiarism is defined as the submission or presentation of work, in any form, which is not one's own, without acknowledgement of the sources. Plagiarism can also arise from one student copying another student's work or from inappropriate collaboration. Allowing someone else to copy your work is just as bad as copying someone else's work yourself. It is vital that you do not allow anyone else to copy your work. Take care when discarding work and do not leave copies of your own files on a hard disk where others can access them. If you have any doubt as to what level of discussion is acceptable, you should consult your lecturer or the Course Director.

The incorporation of material without formal and proper acknowledgement (even with no deliberate intent to cheat) can constitute plagiarism.

With regard to essays, reports and dissertations, the rule is: if information or ideas are obtained from any source, that source must be acknowledged according to the appropriate convention in that discipline; and any direct quotation must be placed in quotation marks and the source cited. Any failure to acknowledge adequately or to properly cite sources of information in submitted work constitutes an act of plagiarism.

Plagiarism is considered to be an act of fraudulence and an offence against University discipline. Alleged plagiarism will be investigated and dealt with appropriately by the University.

The University Plagiarism statement is available from:
http://senate.gla.ac.uk/academic/plagiarism.html

Please complete the information below in BLOCK CAPITALS.

Name ANDREA GALLAGHER

Matriculation Number 0807828

Course Name DOCTORATE IN CLINICAL PSYCHOLOGY

Assignment Number/Name CLINICAL RESEARCH PORTFOLIO

DECLARATION:

I am aware of the University's policy on plagiarism and certify that this assignment is my own work.

Signed……..…….. Date…….

Acknowledgements

First and foremost I would like to thank my research supervisors Professor Andrew Jahoda and Dr Jaycee Pownall. Their patience, support, and guidance has been invaluable in devising, implementing and writing this research.

I would like to thank all of the support staff who took time to complete questionnaires and share their experiences of supporting the service users they work with. Without your help this research would not have been possible.

I would like to acknowledge my clinical supervisors for the knowledge and assistance they have given me during my training.

I would like to say a big thank you to my study group and fellow trainees who offered friendship and invaluable support when needed, making my training experience both memorable and enjoyable.

I am grateful for the endless encouragement my family and friends have given me, both in applying for, and working through, this training course. To Kathleen and Geraldine, you both were always there to offer me support when needed and I'm looking forward to spending more time with you, and of course little Lucy! A huge thank you goes to my wonderful partner David. Your unfaltering encouragement helped me to keep going. You have always been there for me, whether it's making me smile through the stress, taking care of things round the house and reminding me that I can do this! Last, but definitely not least, my mum and dad. You have always believed that I can do anything I set my heart on, and it's your faith in me that has helped me achieve all that I have. I don't think I would have got this far without your help and support. Thank you for always being there.

Table of Contents

	Page
Declaration of Originality Form	**1**
Thesis Access Declaration Form	**2 – 3**
Acknowledgements	**4**
Volume I	
Chapter 1	
Systematic Literature Review	**7 – 47**
A distinct relationship: do support staff who work with people with intellectual disabilities hold liberal attitudes towards their sexuality?	
Chapter 2	
Major Research Project	**48 - 85**
Investigating staff's attitudes and willingness to support men and women with intellectual disabilities on matters relating to their sexuality.	
Chapter 3	
Advanced Clinical Practice I: Reflective Account (Abstract only)	**86 - 87**
Facilitating reflective practice within a multidisciplinary team trained in psychosocial interventions: roles, responsibilities and resistance.	
Chapter 4	
Advanced Clinical Practice II: Reflective Account (Abstract only)	**88 - 89**
Developing the role of the clinical psychologist: managing barriers to self progress when working in teams.	

Appendices		**Page**
Appendix A	Requirements for submission to *Journal of Intellectual Disability Research*	**90**
Appendix B	Participant Background Information Sheet	**91 - 92**
Appendix C	Semi-Structured Interview	**93 - 95**
Appendix D	Attitudes to Sexuality Questionnaire (Men with Intellectual Disabilities) & Attitudes to Sexuality Questionnaire (Women with Intellectual Disabilities)	**96 - 99**
Appendix E	Ethical Approval Letter	**100**
Appendix F	Participant Consent Form	**101**
Appendix G	Participant Covering Letter	**102**
Appendix H	Participant Information Sheet	**103 - 105**
Appendix I	Flow Chart of Recruitment	**106**
Appendix J	Example Quotes from Semi-Structured Interviews	**107 - 111**
Appendix K	Major Research Project Proposal and Addendum	**112 - 133**

Volume II (Bound Separately)

Chapter 3

Advanced Clinical Practice I: Reflective Account **2 - 18**

Facilitating reflective practice within a multidisciplinary team trained in psychosocial interventions: roles, responsibilities and resistance.

Chapter 4

Advanced Clinical Practice II: Reflective Account **19 - 34**

Developing the role of the clinical psychologist: managing barriers to self progress when working in teams.

Chapter 1: Systematic Literature Review

A distinct relationship: do support staff who work with people with intellectual disabilities hold liberal attitudes towards their sexuality?

Author: Andrea Gallagher*[1]

Mental Health and Wellbeing, University of Glasgow*

Address for Correspondence[1]

University of Glasgow

Mental Health and Wellbeing

Gartnavel Royal Hospital

1055 Great Western Road

Glasgow

G12 0XH

Tel: 0141 211 3920

Fax: 0141 211 0356

Email: a.gallagher.1@research.gla.ac.uk

KEYWORDS: intellectual disability, attitudes, staff, sexuality

Submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology (D. Clin. Psy.)

Prepared in accordance with requirements for submission to: *Journal of Intellectual Disability Research (Appendix A)*

Abstract

Background

Historically attitudes to sexuality for people with intellectual disabilities (ID) have been reported as conservative and restrictive. In recent years advances have been made in the rights and quality of life for people with ID. Support staff have an important role in assisting the lifestyles of the service users they work with, hence understanding their attitudes to sexual matters is important. This systematic review explores the recent research investigating support staff's attitudes on this topic.

Method

A search of relevant electronic databases, key journals and reference list was carried out to indentify papers. Eight studies were included in this review and a quality rating tool was used to explore findings.

Results

Support staff were found to hold relatively liberal attitudes. Nevertheless, some studies found that attitudes to particular aspects of sexuality, such as parenting, were less liberal. Findings were discussed in relation to the attitudes of relevant comparison groups such as parents of people with ID.

Conclusions

Further research is required to explore whether staff's attitudes impact on the support they offer service users on sexual matters.

Introduction

Forming personal relationships is an important aspect of a person's life and developing a positive sexual identity has been linked to individuals' emotional wellbeing (Ailey et al., 2003). Nonetheless, during the early twentieth century many individuals with intellectual disabilities (ID) lived in institutions where they were often segregated and the opportunities to develop sexual relationships were limited. Many people with an ID were sterilised against their will (Craft & Craft, 1981). Generally, negative attitudes were held about the sexuality of people with ID (Craft & Craft, 1981). Over time, opinions have become less restrictive, however, carers often still hold cautious views about the sexuality of people with ID (McCabe, 1999). Understanding staff's attitudes to sexuality for people with ID is important, as staff have a considerable influence on the interpersonal relationships of the individuals they support.

Many people with ID are socially excluded and thus may rely on support staff for assistance with various aspects of their lives. Forrester-Jones et al. (2006) reviewed the social networks of 214 people with ID and found that individuals were most likely to seek emotional and practical assistance from support staff. Agar et al. (2001) also found that staff members and/or other peers were the most likely sources of support for adults with ID. In addition, it was found that few contacts were made with other people from the general population, for example neighbours. Pownall (2010) reported that young people with ID were less likely to discuss sexual issues with their peers and were found to have inaccurate knowledge on sexual matters. Moreover, an individual's sexuality is a very private matter, and people with ID have reported feeling wary about accessing information or support about sexual matters, in part, due to fears that those they seek support from may react negatively (Morrison, 2007).

As such, it is important that people with ID have supportive staff members who hold positive views about their sexuality and are willing to assist with sexual matters. This would help to ensure that service users' sexuality is developed and expressed in a healthy, safe way.

A liberal attitude can be defined as a way of thinking which is tolerant and open minded (Oxford English Dictionary, 2011). Measures which have been developed to explore staff's attitudes to sexuality, for instance the Attitudes to Sexuality Questionnaire – Individuals with an Intellectual Disability (ASQ-ID; Cuskelly & Gilmore, 2007), have investigated whether staff hold liberal attitudes, that is if staff have positive or accepting attitudes to the sexuality of people with an ID. It could be considered that staff who hold liberal attitudes are more likely to be accepting of people with an ID having opportunities to develop relationships, express their sexuality and make informed choices about their sexual matters regardless of whether they agree with the choices individuals with ID make. This could cover different aspects of sexuality such as sexual health matters, parenting and intimate relationships. As staff play a significant role in the lives of people with ID, their beliefs may impact not only on the support that service users receive for sexual matters but also their opportunities to develop positive and fulfilling relationships.

This link between a person's attitudes and their behaviour has been explored within the Theory of Reasoned Action (TRA; Fishbein & Ajzen, 1975) and developed further within the Theory of Planned Behaviour (TPB; Ajzen, 1991). Both theories propose that subjective norms and a person's attitudes determine their behavioural intentions, predicting behaviour itself. The formation of attitudes is influenced by a person's beliefs about the outcome of behaviour and their evaluation of this outcome. Such salient beliefs can be influenced by

demographic variables such as age. For instance, via their salient beliefs, demographic factors associated with staff holding liberal attitudes to service users' sexuality include staff being of a younger age (Cuskelly & Bryde, 2004) and holding professional qualifications (Murray & Minnes, 1994). The link between staff's salient beliefs about supporting service users with sexual matters and their attitudes to sexuality for people with ID remains unexplored. The Theory of Planned Behaviour further suggests that a person's perceived behavioural control, that is their perceived ease or difficulty of performing a behaviour, will impact on their behavioural intentions and the behaviour itself. Hence, though attitudes do not directly predict behaviour, both theories would propose that staff who hold liberal attitudes to the sexuality of people with ID could be more likely to support them with their sexual needs. As a result it is important to understand whether staff hold positive attitudes to sexual matters for people with ID.

Previous research examining the attitudes of support staff found that less liberal or ambivalent views were expressed about the sexuality of people with an ID (Chapman & Pitceathly, 1985). Mitchell et al. (1978) reported that the majority of staff they interviewed felt that it was acceptable if people with ID were asexual. Craft and Craft (1981) carried out a review, reporting research which indicated that staff held less liberal, restrictive views on sexuality for this population of people. Nonetheless, Craft and Craft's (1981) review also discussed that attitudes were shifting in a positive way. More recent studies have demonstrated that staff attitudes may have become more liberal, although individuals providing direct care to people with ID have been found to hold less liberal views than professional staff (Murray & Minnes, 1994).

Although staff may have personal opinions on sexuality and disability, legislation is available which details the rights that people with an ID have to make decisions about their personal lives. The Adults with Incapacity (Scotland) Act (Scottish Government, 2000) outlines that those with capacity should be supported to make their own decisions irrespective of whether they make unwise choices. Nonetheless, research indicates that staff do not always receive adequate training on guidelines and policies regarding supporting service users' sexuality and instead may rely on their personal beliefs to guide their practice (Ward et al., 2001). Moreover, staff's views on assisting service users with sexual matters may be influenced by the competing demands of their role. This in part may stem from risk factors and concerns regarding the vulnerability of individuals with ID to exploitation (Garbutt, 2008), and could motivate staff to take a protective role regarding sexual matters. Grieve et al. (2008) found that some staff believed that if they did not intervene when service users became sexually active, they could be at risk of being prosecuted. Conversely, individuals with an ID have reported that they value the supportive input that staff provide on sexual matters, for instance sex education (Morrison, 2007). Thus staff's role also involves helping individuals to lead independent lives, which includes supporting the development of their sexuality. Due to these competing roles of promoting people's sexuality on the one hand and protecting against exploitation on the other, it would not be predicted that that staff simply hold liberal attitudes to the sexuality of people with ID.

This review aims to examine support staff's changing attitudes towards sexual matters for people with ID. To do this the review will examine findings from research papers published within the last decade.

Review Question

Do support staff who work with people with intellectual disabilities hold liberal attitudes towards their sexuality?

Search Strategy

Electronic Database Search and Search Terms

Research articles were extracted from peer reviewed journals from the following electronic databases: Ovid Medline (1948 – April week 2 2011), EMBASE (1988 – 2011 week 16), ERIC (1965 – March 2011), HMIC (1979 – March 2011), All EBM Reviews (Cochrane Database of Systematic Reviews 2005 to March 2011, ACP Journal Club 1991 to March 2011, Database of Abstracts of Reviews of Effects 2nd Quarter 2011, Cochrane Central Register of Controlled Trials 1st Quarter 2011, Cochrane Methodology Register 2nd Quarter 2011, Health Technology Assessment 2nd Quarter 2011, NHS Economic Evaluation Database 2nd Quarter 2011), PsycINFO, CINAHL Plus with Full Text, Psychology and Behavioral Sciences Collection, Social Policy & Practice and British Nursing Index (1994 – November 2010). A limit on articles published from the year 2000 onwards was applied.

The following search terms were used for the electronic search: (Intellectual Disability *or* Intellectual Difficulty *or* Intellectual Impairment *or* Intellectual Retardation *or* Intellectual Deficiency *or* Intellectual Handicap *or* Mental Disability *or* Mental Difficulty *or* Mental Impairment *or* Mental Retardation *or* Mental Deficiency *or* Mental Handicap *or* Developmental Disability *or* Developmental Difficulty *or* Developmental Impairment *or* Developmental Retardation *or* Developmental Deficiency *or* Developmental Handicap *or*

Learning Disability *or* Learning Difficulty *or* Learning Impairment *or* Learning Retardation *or* Learning Deficiency *or* Learning Handicap *or* Mentally Disabled Person) and (Support Staff *or* Staff *or* Home Care *or* Long Term Care *or* Social Support *or* Day Centre *or* Community *or* Home Care Services *or* Domiciliary Care *or* Home Nursing *or* Intellectual Disability Services) and (Sexuality *or* Sexual Behaviour *or* Sex Education *or* Sexual Intercourse *or* Sexual Orientation *or* Homosexuality *or* Heterosexuality *or* Masturbation *or* Sexual Practice *or* Sexual Health *or* Physical Relationship *or* Sexual Relationship) and (Attitude *or* Judgement *or* Belief *or* View *or* Opinion). Truncation was applied to all search terms.

Hand Search

A hand search was carried out within The Journal of Intellectual & Developmental Disability, Sexuality and Disability, British Journal of Learning Disabilities, Journal of Applied Research in Intellectual Disabilities, Learning Disability Practice and Journal of Intellectual Disability Research, as relevant articles were uncovered from these journals during the electronic search. Journal articles published from the year 2000 onwards were searched. The reference lists of key articles and review papers were also searched for relevant articles.

Criteria for Inclusion and Exclusion

The following inclusion and exclusion criteria were applied to all articles found within the electronic and hand searches:

Inclusion Criteria: i) studies examining support staff's attitudes towards adults with ID with regards to sexuality/sexual matters, ii) studies which explored both support staff's attitudes

and the attitudes of family members, lay-persons or other professionals towards the sexuality of adults with ID and non disabled people, iii) studies published from the year 2000 onwards, iv) quantitative studies.

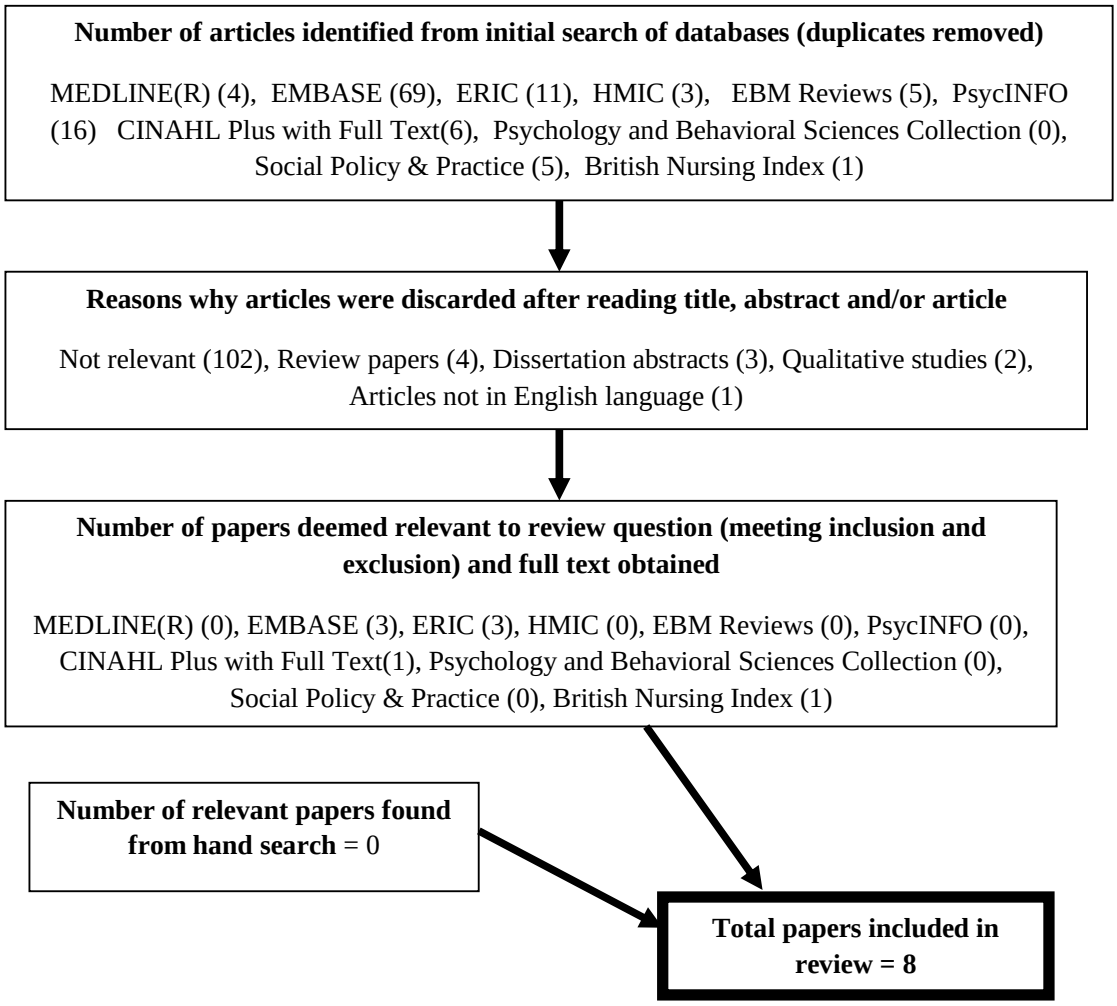
Exclusion Criteria: i) studies using only qualitative methodology, ii) review papers, iii) dissertations, iv) studies not published in the English language.

Article Extraction

The inclusion and exclusion criteria were applied to all studies returned from the electronic and hand search. With duplicated articles removed, 120 articles remained from the electronic database search, 112 articles did not meet the inclusion/exclusion criteria leaving 8 articles. A hand search did not uncover any further relevant articles, hence 8 articles in total were identified for this systematic review. Figure 1 is a flow chart that details the search.

Figure 1

Flow chart of articles obtained from electronic and hand search



The following information was extracted from papers that fitted the inclusion/exclusion criteria; i) the design of the study, ii) the aim(s), iii) sample characteristics, iv) measures used and the quality of the measures, v) results, vi) methodological strengths and weaknesses. Data extraction tables were used to gather this relevant information.

Quality Criteria

As the studies included in this review do not concern the outcome of an intervention, established quality rating scales such as CONSORT guidelines (Altman et al., 2001) and CASP (Critical Appraisal Skills Programme, 2006) were not appropriate. Instead a rating scale was devised to assess the quality of the studies included in this review (Table 1). This rating scale includes key information referenced by guidelines. Additional methodological factors relevant to this review, such as measures used and analysis, were also included.

This review aims to examine support staff's attitudes towards the sexuality of people with ID. Consequently, articles that i) compared attitudes towards adults with ID with attitudes towards adults in the general population, and ii) compared support staff's attitudes to those of another comparison group(s) were considered the most effective design. Studies using this design helped to identify whether staff, in particular, held attitudes specifically towards people with ID. These papers were categorised as Design A. The studies that compared the attitudes of support staff with the attitudes of another group of people towards those with ID only were categorised as Design B. Those studies without a comparison group were considered the weakest design and categorised as Design C. Six additional quality criteria deemed important to consider were also included in the rating scale, and are shown in Table 1

below. The quality of the studies were ranked according to design, and the review will examine the articles within each of the design categories in turn.

Table 1: Quality Rating Scale

Quality Item: Design	**Criteria**	**Coding**
Design A	Cross sectional: exploring staff's attitudes and the attitudes of a relevant comparison group to sexual matters for people with intellectual disabilities and for people in the general population.	A
Design B	Cross sectional: exploring staff's attitudes and the attitudes of a relevant comparison group to sexual matters for people with intellectual disabilities.	B
Design C	Cross sectional: exploring staff's attitudes to sexual matters for people with intellectual disabilities.	C

Quality Item	**Criteria**	**Coding**
Research Question	Focussed with clear aims	2
	Partially focused	1
	Not clear	0
Sample	Geographical sample	2
	Convenience sample	1
	Not clear	0
Participant Characteristics	Sample characteristic reported • Well Addressed • Adequately Addressed • Poorly Addressed • Not Clear	 3 2 1 0
Measures of Attitudes	Reliability and/or validity reported, measure appropriate for assessment of attitudes towards target population:	3

	• Well Addressed • Adequately Addressed • Poorly Addressed • Not Clear	2 1 0
Analysis	Appropriate statistical analysis carried out, analysis takes into account level of ID, power calculation reported: • Well Addressed • Adequately Addressed • Poorly Addressed • Not Clear	 3 2 1 0
Discussion	Finding related to aims/hypotheses, attempts to interpret results in relation to theory and previous findings, limitations clearly expressed, recommendations for clinical practice/future research : • Well Addressed • Adequately Addressed • Poorly Addressed • Not Clear	 3 2 1 0

The papers included in this review were assessed using this rating scale by the author. To ensure the reliability of the ratings, a second independent rater reviewed each paper. The Kappa statistic was used to analyse inter-rater reliability and was found to be Kappa = 0.80. Discrepancies were discussed and 100% agreement reached. Table 2 illustrates the scoring of each article based on this rating scale.

Table 2: Review article scores on the quality rating scale

Study	Design Rating	Research Question	Sample	Participant Characteristics	Measure of Attitudes	Analysis	Discussion	Total Score
Gilmore & Chambers (2010)*	A	2	1	3	3	2	3	14
Oliver et al. (2002)	A	2	1	3	2	2	3	13
Drummond (2006)	A	2	1	2	2	2	3	12
Bazzo et al. (2007)**	B	2	2	3	3	2	3	15
Grieve et al. (2008)	B	2	1	3	3	3	2	14
Cuskelly & Bryde (2004)	B	2	1	3	3	2	3	14
Evans et al. (2009)	B	2	1	3	0	0	3	9
Christian et al. (2001)	C	2	1	3	0	0	1	7

***paper rated as the highest quality paper categorised as Design A, **paper rated as the highest quality paper categorised as Design B.**

Results

The first section of this review will examine the papers that are categorised within Design A (n = 3), the second section will examine the evidence found in papers categorised as Design B (n = 4), and the third section will discuss findings from the paper categorised as Design C (n = 1). Though the quality of the Christian et al. (2001) paper categorised within Design C was rated the lowest, it was considered important to include it in the review as some of the results found from this study were reflected within the higher quality papers. In addition, this paper explored staff attitudes to sexual matters for women with an ID who have specific support needs, for instance with gynaecological issues. As a result it was considered appropriate to explore the paper's findings despite its methodological weaknesses.

Key characteristics of each of the papers will be briefly discussed below, with a summary description provided in the data extraction tables. The findings in relation to staff's attitudes for each of the design categories will be reviewed before considering methodological issues. Conclusions based on the findings and taking account of methodological issues will be made.

Design A Studies

Three papers were categorised within Design A; Gilmore & Chambers (2010), Oliver et al. (2002) and Drummond (2006). The study details are briefly described in Table 3.

Table 3	**Design A Data Extraction Table**		
Study & Sample characteristics	Measure & reported quality of measure	Relevant Results	Methodological Considerations
Gilmore & Chambers (2010) Group 1: 169 support staff (69% female) Age 20 – 70+ Group 2: 50 leisure and service industry employees (88% female) Age: 20 – 69	Attitudes to Sexuality Questionnaire – Individuals with an Intellectual Disability reported high test-retest reliability (r = 0.91), good internal consistency (α > 0.90), 4 subscales: 1) Self control, 2) Parenting, 3) Non-reproductive sexual behaviour, 4) Sexual rights Attitudes to Sexuality Questionnaire – Individuals from the General Population: internal consistency reported for the questions on the 'sexual openness' factor, not for the questions within the 'timing' factor. 2 subscales: 1) Sexual openness, 2) Timing	Attitudes to people with ID: • Both groups - overall liberal attitudes to people with ID. No significant differences between groups • Significant difference between groups towards parenting: staff – less liberal attitudes. • Both groups - sexual freedom more acceptable in typically developing (TD) people than ID people. • Leisure workers - males with ID have less self control than females. • Both groups - a lower level of sexual freedom desirable for ID women compared to TD women.	Strengths: Level of ID identified for respondents to assess attitudes on. • Internal consistency reported for both measures. • Measure explores attitudes to various aspects of sexuality. • Large sample. Limitations: No definition of the level of ID for respondents to base attitudes upon. • No power calculation.
Oliver et al. (2002) Group1 (staff): 89 (74% female), mean age: 32 (SD 9.5). Group 2 (early adulthood): 148 (62% female), mean age: 20 Group 3 (late adulthood): 42 (57% female), mean age: 77	Author developed an 18 item questionnaire based on previous studies. No reported quality of measure.	• Late adulthood group held less liberal attitudes to people with ID compared to those without on dating, marrying and having children when married. • No difference found in staff's acceptance of sexual behaviours based on level of ID.	Strengths: Attitudes explored in relation to age • Assessed staff's attitudes towards people with different levels of ID. Limitations: No power calculation. • No validity or reliability reported. • Each participant not assessed on both attitudes to people with and without ID. • Undergraduates and seniors not guided on the level of ID to rate attitudes on. • No reference on how levels of ID were categorised for participants.
Drummond (2006) N = 45 (10 male, 35 female) Age: 28 ≤ 50 yrs, 17 ≥ 50 yrs Relationship to persons with ID: 18 parents, 27 staff Level of ID: 26 mild, 19 moderate	The Sexuality Attitudes Questionnaire – Intellectual Disabilities. 4 subscales: 1) Human Sexuality, 2) Acknowledgement of the Sexuality of the Intellectually Disabled 3)Discrimination against the Sexuality of the Intellectually Disabled 4) Attitudes Towards Homosexuality Among the Intellectually Disabled. Reliability (α = 0.93)	• Moderate attitudes found. No difference between the two groups on overall scores on SAQ-ID. • Significant difference found: Highest median score found for the Human Sexuality subscale and lowest median score found for Attitudes Towards Homosexuality Among the Intellectual Disabled. • Differences in the Attitudes to Homosexuality subscale: staff had more liberal attitudes than parents.	Strengths: Measure explores attitudes to various aspects of sexuality • Reliability reported. Limitations: Characteristics of the two groups not discussed separately • Small sample size, no power calculation. • No explanation of difference between the original GSAQ-LD and the SAQ-ID. • Validity unknown. • Level of ID not defined for participants to rate their attitudes on.

Gilmore & Chambers (2010) explored support staff's (n = 169) attitudes to sexuality in men and women with mild/moderate ID and compared this to the attitudes of leisure industry employees (n = 50) using the modified version of The Attitudes to Sexuality Questionnaire - Individuals with an Intellectual Disability (ASQ-ID; Cuskelly & Gilmore, 2007). Attitudes to men and women without an ID were also explored using the Attitudes to Sexuality Questionnaire - Individuals from the General Population (ASQ-GP; Cuskelly & Gilmore, 2007). All participants completed the ASQ-ID and the ASQ-GP.

Oliver et al. (2002) explored attitudes towards the acceptability of socio-sexual behaviours for people with an ID and without an ID in three groups of individuals i) residential support staff (n = 89), ii) individuals from the general population in early adulthood (18 – 29 yrs, n = 148), and iii) individuals in the general population in late adulthood (65+ yrs n = 42). The authors developed a questionnaire based on Lunsky & Konstantareas' (1998) study exploring the attitudes of people with ID and autism towards sexual behaviours.

Drummond (2006) carried out a study to assess staff's (n = 27) and parents' (n = 18) attitudes to sexuality in relation to adults with a mild or moderate ID who accessed the same day service that staff worked in. Attitudes towards sexuality for people in the general population, attitudes towards homosexuality in people with ID and discriminatory attitudes towards the sexuality of people with ID were explored. Attitudes were assessed using the Sexual Attitudes Questionnaire – Intellectual Disabilities adapted by the authors from the Greek Sexual Attitudes Questionnaire – Learning Disabilities (Karellou, 2003).

Findings

Overall, staff (Gilmore and Chambers, 2010; Oliver et al., 2002; Drummond, 2006), parents (Drummond, 2006), leisure workers (Gilmore and Chambers, 2010) and members of the general population (Oliver et al., 2002) were found to have moderately liberal attitudes towards the sexuality of people with ID. In general, staff attitudes were found to be supportive of sexuality for people with ID, however, some studies found that less accepting attitudes were held in comparison with attitudes to those in the general population and on specific aspects of sexuality such as homosexuality and parenting.

Comparing staff's attitudes to the attitudes of relevant others

Gilmore and Chambers (2010) found that there were no differences between staff's and leisure workers' attitudes towards sexual rights, non-reproductive sexual behaviour and self-control for people with ID. Nevertheless, differences were found on the parenting subscale, with staff holding more conservative attitudes than leisure workers. Drummond (2006) found no overall difference between the attitudes of staff and parents. Nonetheless, on the subscales, Drummond found that staff held more open attitudes towards homosexuality for people with ID than their parents did. Compared to the attitudes of staff and younger aged people in the general population, the older participants in Oliver et al's (2002) study held less liberal attitudes towards people with ID in terms of dating, marrying and having children when married. These results indicate that although generally liberal attitudes are held by staff regarding sexuality for people with ID, they hold more conservative views specifically about parenting. Older members of the general population were also less positive about parenting, along with dating and marrying, whereas parents of individuals with ID held unfavourable views about homosexuality.

Comparing attitudes towards people with ID to people without ID

When examining attitudes towards people with an ID compared to individuals in the general population, Oliver et al. (2002) found no difference in attitudes of staff or the attitudes of the sample of younger people. Yet the older sample of participants from the general population held less liberal attitudes to people with ID than those without ID. Gilmore and Chambers (2010) found that both staff and leisure industry workers viewed sexual freedom as less desirable for women with ID compared to typically developing women. Such a difference was not apparent with men. Drummond (2006) also found more restrictive views towards people with ID compared to those without, with the least liberal attitudes expressed towards homosexuality in people with ID. Nevertheless, their analysis on this explored parents' and staff's attitudes together, so it remains unclear whether such views were held by one or both groups of caregivers. These findings suggest that less liberal views still remain towards people with an ID compared to those without an ID, and specifically towards homosexuality and women.

Impact of level of ID and gender of the person with an ID on attitudes

Further analyses were carried out to examine if there were differences between attitudes held towards men and women, and people with different levels of ability. Oliver et al. (2002) found no difference in staff's acceptance of the sexual behaviour displayed by people with mild/moderate or severe/profound ID. Gilmore and Chambers (2010) explored attitudes towards men and women with ID and found that leisure workers viewed men as having less self-control than women. A trend towards significance was also found regarding staff's attitudes on this matter.

Methodological Issues

Studies categorised as Design A were considered as being more robust, as they obtained the attitudes of a second group of participants and compared attitudes to people with ID with attitudes held about people in the general population. Nonetheless, there are a number of methodological limitations with these studies which mean the findings need to be considered with caution.

Measures

All three studies used different measures to collect information on attitudes. The validity of the measures used was not reported. However, internal consistency of the measures used by Gilmore and Chambers (2010; $\alpha > 0.90$), and Drummond (2006; $\alpha = 0.93$) was stated. The measure used by Gilmore and Chambers (2010) also had reported inter-rater reliability ($r = 0.91$). Oliver et al. (2002) reported neither the reliability nor validity of the measure they used. The measures used by Oliver et al. (2002) and Drummond (2006) were adapted from previous questionnaires. Nevertheless, the original measures were developed for different populations and neither study reported the adaptations made.

Power

Gilmore and Chambers (2010) and Oliver et al. (2002) both had large sample sizes, while Drummond (2006) had a smaller sample size. Nevertheless none of the studies reported whether they had conducted a power calculation to see if statistical power was sufficient. Without a power calculation the results are vulnerable to a type II error (the test fails to reject

a false null hypothesis). As power calculations were not carried out in any Design A study it is uncertain if such an error was made by the authors.

Level of disability

When synthesising the findings from the three studies it is also worth noting that staff's attitudes may concern individuals with different levels of ID. All three studies advised their participants on the category of ID to rate their attitudes upon. Participants in Drummond's (2006) study were asked to consider a familiar person with a mild or moderate ID when completing the measures. Nonetheless, there was no record of the level of disability that participants' responses were based upon. With Oliver et al's (2002) study, the staff group rated their attitudes for an individual with either a mild/moderate or severe/profound ID. Gilmore and Chambers (2010) advised participants to rate attitudes to people with a mild/moderate ID. The ability range within these classifications was large, and it is unknown if definitions of the classifications were provided. This is important to note as it is possible that attitudes would differ depending on a person's support needs and hence their level of disability.

Conclusions

Design A papers found that generally liberal attitudes were held towards the sexuality of people with ID. Attitudes were found to differ based on the gender of the target individuals with ID, and variations in acceptable sexual practices and relationships were found between staff, parents, and older aged lay people. Less liberal attitudes were found for people with ID compared to the general population. Due to the methodological limitations discussed it is

unknown if these attitudes apply to people with particular classifications of disability or if different results would be found if measures with proven validity were used.

Design B Studies

Four papers were categorised within Design B; Grieve et al. (2008), Evans et al. (2009), Bazzo et al. (2007) and Cuskelly & Bryde (2004). The studies are outlined in Table 4 below.

Table 4	**Design B Data Extraction Table**		
Study & Sample characteristics	Measure & reported quality of measure	Relevant Results	Methodological Considerations
Grieve et al. (2008) Group 1: 148 Care staff (84.4% female, mean age 37.6) Group 2: 40 Qualified nursing staff (80% female, mean age 42.9)	The Sexual Attitudes Questionnaire measures attitudes towards: • Homosexuality • Heterosexuality • Masturbation • Sexual and non-sexual behaviours Reliability (α = 0.083; Rose & Holmes, 1991) and validity reported	No difference between support staff and qualified nursing staff on: • homosexual and heterosexual attitudes, • attitudes towards individuals with a mild, moderate and severe/profound ID • the overall attitude score.	Strengths: Classification provided to participants on level of ID to base attitudes on taken from International Classification of Diseases and Related Health Problems (1992). • Statistical power calculated. • Reliability and validity of measure reported. Weaknesses: Study is underpowered.
Evans, et al. (2009) Group 1: 155 Staff (88% female), mean age 40 Group 2: 153 Family carers (80% parents (86% female), 19% siblings (85% female)) mean age: 54	Questionnaire (devised by authors) assessed attitudes on: i) Discussing sexuality with service users, ii) Education and training, iii) Sexual rights of service users, vi) Views about service user relationships. Quality of measures not reported.	Family carers indicated a preference for non-intimacy in relationships compared to staff carers who were more likely to support engagement in intimate and non-intimate relationships and unsupervised relationships.	Strengths: explores attitudes on various aspects of sexuality and on different ID levels. Weaknesses: quality of measures not reported. • Does not explain how level of ID is defined. • Statistical tests used not specified • No power calculation.
Bazzo et al. (2007) 216 social service providers (managers, educators, direct care staff, 74.5% female) Mean age: 35.5	20 item subscale of 40 item Sexuality and Mental Retardation Attitudes Inventory used. Reliability (α = 0.80).	Liberal attitudes found. No significant differences across roles.	Strengths: reliability of measure reported Limitations: Validity of measure not reported • Did not specify level ID to assess attitudes on. • No power calculation.
Cuskelly & Bryde (2004) Group 1: 62 support staff (68% female), Age range = 41 – 60+ yrs Group 2: 43 parents (84% mothers), Age range = 41 – 60 yrs Group 3: 63 individuals from a community sample (59% female), age range = < 21 – 60+ yrs	Attitudes to Sexuality Questionnaire – Individuals with an Intellectual Disability: 8 themes: i) sexual feelings, ii) sex education, iii) masturbation, iv) personal relationships, v) sexual intercourse, vi) sterilisation, vi) marriage, viii) parenthood Test-retest reliability (r = 0.91), internal consistency (α > 0.90)	• Generally positive views found. • Age had significant impact on attitudes: oldest group (parents) held less positive attitudes than other groups. With age as a covariant there were no group or gender differences. • Parents held less liberal attitudes on parenting than staff with a trend towards significance. • Parent and staff group were less positive about parenthood than other aspects of sexuality.	Strengths: Instructed to focus attitudes towards levels of moderate ID . • Attitudes investigated on broad range of sexual matters. • Reliability reported for scale. Limitations: Parent and staff participants given varying definitions of moderate ID to base attitudes upon. • No power calculation. • Validity of measure unknown.

Grieve et al. (2008) explored attitudes of qualified nursing staff (n = 40) and support staff (n = 148) working in different residential settings towards the sexuality of people with ID. Attitudes to people with mild, moderate or severe/profound ID were assessed using the Sexual Attitudes Questionnaire (SAQ; Mitchell et al., 1978). Classifications of levels of ID were provided to participants from the International Classification of Diseases and Related Health Problems (1992).

Evans et al. (2009) assessed attitudes of staff (n = 155) working in a community based service for people with ID and family carers (n = 153; 80% parents, 19% siblings) who utilised the same service. Attitudes were assessed via a questionnaire developed by a working group of professional support staff, care staff and relatives of people with ID. The measure was also informed by knowledge gathered from service user focus groups.

Bazzo et al. (2007) assessed attitudes of managers (n = 45), educators (n = 77) and direct care staff (n = 94) working in different services for people with ID in the north east of Italy. Participants completed a 20 item subscale of the 40-item Sexuality and Mental Retardation Attitudes Inventory (SMRAI; Brantlinger, 1983, Murray & Minnes, 1994).

Cuskelly & Bryde (2004) assessed the attitudes of support staff (n = 62), parents who's offspring attended the same service that staff worked within (n = 43) and people in a community sample (n = 63), towards the sexuality of people with a moderate ID. Items were taken from previous attitude assessments (Fischer et al., 1973; Mulhern, 1975; Parsons, 1982; Sweyn-Harvey, 1984) to develop the attitude scale used to elicit the participants' answers (Attitudes to Sexuality Questionnaire – Individuals with an Intellectual Disability, ASQ-ID).

Findings

Once again, support staff were generally found to have positive attitudes about the sexuality for people with ID.

Comparing staff's attitudes with the attitudes of relevant others

Bazzo et al. (2007) found no significant differences between the attitudes of support staff, educators and managers working across different establishments. Grieve et al. (2008) also failed to find a difference between support staff's and qualified nursing staff's views about the sexuality of people with ID.

Cuskelly & Bryde (2004) found that, compared to parents of individuals with ID, staff held significantly more liberal attitudes to the sexuality of people with ID, and a trend to significance was found regarding views towards parenting. Nevertheless, the parents were older than the staff members, and when age was controlled for there were no significant group differences. Both staff and parents were less liberal in their views of people with ID becoming parents compared to other aspects of their sexuality. Community group participants did not differ in their attitudes to parenting compared to other sexual matters (Cuskelly & Bryde, 2004).

Evans et al. (2009) examined views on who should be involved when making decisions about capacity to engage in relationships. They found that the majority of staff believed that the person with ID, their parents and staff members should all be involved in relationship

decisions. This differed from the majority of family carers' views that only family members should be involved in such decisions. Evans et al. (2009) also found that significantly more staff than family members agreed that people with ID should be allowed unsupervised relationships. Moreover, a significantly larger proportion of staff compared to family members agreed that parents should not be notified of service user's ongoing relationships (Evans et al., 2009).

Impact of level of ID, gender, and age

Cuskelly and Bryde (2004) assessed parents' attitudes in relation to the age, gender and disability level of their adult children with an ID. Gender and level of disability were not significantly related to attitudes. Nonetheless, a significant association was found between age and attitudes; the older the child the less liberal parents' attitudes. Grieve et al. (2008) also found that the level of ID did not impact on attitudes. Their study found that there was no difference between support staff's and nursing staff's attitudes towards sexuality in people with mild, moderate or severe/profound ID. Nevertheless, Evans et al. (2009) found differences in attitudes based on level of disability; staff were more supportive of friendships and non-intimate relationships compared to intimate relationships and marriage for people with mild, moderate or severe ID. A greater proportion of staff than family carers believed that people with mild or moderate ID could engage in intimate or marital relationships, whereas family carers expressed a stronger support for non-intimate relationships.

Methodological Issues

Measures

Three of the studies categorised as Design B used measures which they reported to be reliable through test-retest reliability (r) and/or internal consistency (α); Cuskelly & Bryde (2004) r = 0.91, α > 0.90; Bazzo et al. (2007) α = 0.80; Grieve et al. (2008) α = 0.883. Only Grieve et al. (2008) reported that the measure they used was valid, however they did not explain this further. The fourth study, Evans et al. (2009), developed a measure based on information gathered from focus groups and working groups, however, the reliability and validity of the measure was not reported. Moreover, though the paper outlines the topics explored in the questionnaire, no information was given on the questions asked to measure attitudes.

Power

Only Grieve et al. (2008) report a power calculation, and they reported that their study was slightly underpowered. The other three Design B studies had fairly large sample sizes but did not report a power calculation. Thus it is unknown if the analyses carried out in these studies were at risk of making a type II error.

Level of disability

Taking account of individuals' level of ID is also a key factor to consider when examining staff attitudes towards their sexuality. Grieve et al. (2008) used ICD-10 (1992) classification of ID to explore attitudes across different levels of impairment. Both Cuskelly and Bryde (2004) and Evans et al. (2009) explored attitudes based on the level of disability. However, it

is not obvious if they used clear and consistent definitions across the participant groups. Bazzo et al. (2007) did not explore attitudes based on level of ID. It could be argued that Grieve et al. (2008), and possibly Cuskelly and Bryde (2004) and Evans et al. (2009) have examined attitudes to sexuality in a more meaningful way as a specific link is made between attitudes and the level of ability of the target individuals.

Impact of age on attitudes

The fact that support staff were significantly older than nursing staff in Grieve et al's (2008) study did not influence their findings and no differences were found between the groups on their attitudes to sexuality. In contrast Cuskelly and Bryde (2004) found that older participants held more conservative views irrespective of their particular role or relationship with individuals with ID.

Conclusions

Staff held more liberal views compared to parents/family carers on sexuality. In terms of sub-categories, similar differences were also found regarding attitudes to parenting, intimate relationships, decision making and privacy in relationships for people with ID. Nonetheless, staff were also found to hold less liberal attitudes on parenting compared to other aspects of sexuality.

Design C

One research paper was categorised within Design C, details of this study can be found in Table 5.

Table 5	**Design C Data Extraction Table**		
Study & Sample characteristics	Measure & reported quality of measure	Relevant Results	Methodological Considerations
Christian et al. (2001) N = 43 (70% female), mean age = 31yrs	41 item survey. No other information on measure provided No reported quality of measure.	• Women with ID viewed as having same sexual desires as those without • Ability to consent should determine whether a woman has a sexual relationship. • Level of disability influenced attitudes towards parenting. • Support for provision of sex education.	Strengths: • Explores sexuality issues pertinent to women. Weaknesses: • No statistical analysis of results carried out. • No power calculation. • Did not specify the level of disability that attitudes are assessed upon. • Lack of information on the survey measure. • No reliability or validity of the measurement used. • Would be unable to replicate results.

Christian et al. (2001) assessed support staff's (n = 43) attitudes to the sexual expression of women with an ID using a 41 item survey. All participants worked within the same agency which provided day services to individuals with ID.

Findings

Overall attitudes to sexuality

The majority of staff surveyed felt that the service they worked in should provide support to women with regard to their sexuality. On the other hand, less than half of respondents agreed that the service recognised women as being sexual individuals. In addition, the majority of staff agreed that women with ID should receive sex education; with over half of staff stating

that they would feel comfortable providing this and supporting women to receive gynaecological care.

Level of disability

Approximately half of staff surveyed agreed that the level of disability would impact on whether women with ID should have a sexual relationship and should determine whether she has children. Although, most agreed that given the right support and training women with ID could be competent mothers. Related to such views, more than two thirds reported that a woman's ability to consent should ascertain whether she has a sexual relationship.

Methodological Issues & Conclusions

This study attempted to explore attitudes towards sexuality issues pertinent to women with ID, including pregnancy and gynaecological health. Unfortunately, there are a number of methodological weaknesses. In the first instance, little is known about the measure used to assess staff's attitudes. For example, no information was provided about how the measure was devised or on its reliability and validity. Hence it is difficult to determine whether the results provide an accurate measurement of the respondents' attitudes. A power calculation was not carried out to determine the correct sample size and statistical analyses were also not used; instead only descriptive results were provided. Thus, even though the descriptive findings fit with those of more robust studies, these methodological limitations mean that they need to be treated with great caution.

Discussion

Historically less liberal attitudes have been reported by staff towards the sexuality of people with ID (Mitchell et al., 1978). This systematic review examined the more recent literature published in the last decade, to explore if support staff's attitudes towards the sexuality of people with ID had shifted towards more liberal views. Thus, this review has particularly focused on whether staff hold positive and accepting attitudes to people with ID's sexuality. All studies included in the review illustrated that staff generally hold liberal attitudes towards sexual matters for people with ID.

To allow for a robust examination of attitudes, this review drew on findings from studies which explored staff's views on the sexuality of people with ID and compared them to their attitudes to the sexuality of people in the general population. By doing so, it allowed the reader to identify if the attitudes held by staff were in relation to a person's intellectual disability, or a reflection of their more general attitudes about sexuality. From these comparison studies, it was found that less liberal/accepting attitudes were held by staff towards sexual freedom for women with ID compared to women in the general population (Gilmore and Chambers, 2010). In addition less positive attitudes were held about homosexuality for people with ID compared to people in the general population (Drummond, 2006). Importantly, Oliver et al. (2002) did not find any differences in support staff's attitudes to the sexuality of people with ID compared to typically developing people. It is possible that staff's less liberal attitudes towards sexual freedom for women with ID is a reflection of their concerns regarding women's wellbeing, as research indicates women with ID are vulnerable to sexual exploitation (McCarthy and Thompson, 1997). It would be interesting to find out why less liberal attitudes are held by staff towards homosexuality for

people with ID. It is possible that such attitudes may also be related to concerns regarding service users' wellbeing such as their understanding of safe sex practices.

Studies included in this review also compared attitudes of staff to a relevant comparison group, allowing a further measurement on whether staff's attitudes were similar to those of other groups, including family, other professionals and lay people. Two studies found that there were no differences between staff's and other professionals' attitudes towards the sexuality of people with ID (Bazzo et al., 2007; Grieve et al., 2008). Varying results were found regarding attitudes towards people with ID becoming parents; staff were found to hold less accepting attitudes compared to lay people on this topic (Gilmore and Chambers, 2010). Conversely, Oliver et al. (2002) found that staff reported more liberal views towards parenting than older people from the general population. Cuskelly and Bryde (2004) stated that both staff and parents reported less liberal attitudes towards people with ID becoming parents compared to other aspects of sexuality, with parents holding the least liberal attitudes compared to staff. Importantly, when age was controlled for differences between parents' and staff's attitudes were not upheld. This association between younger age and less liberal attitudes is support by the TRA (Fishbein & Ajzen, 1975) and the TPB (Ajzen, 1991) which postulate that demographic factors influence the formation of attitudes. The fact that disparity exists between the two groups of caregivers on people with ID becoming parents, even if influenced by age, requires consideration. Both groups of caregivers have an influence on the people with ID they support. Thus, differences in opinions could lead to issues of conflict regarding the assistance that people with ID receive on sexual matters. Less liberal attitudes towards parenting have been found in previous research (Brantlinger, 1992). It is possible that such attitudes found towards parenting in this review are related to concerns about the support needs people with ID are likely to require if they have children (Christian et

al., 2001). However, research is needed to explore the barriers to more accepting attitudes towards parenthood. This is particularly important, as staff's attitudes on this matter could influence the assistance that they provide people with ID regarding choices on using contraceptives and making informed decisions about having a child.

Results from this review indicated that staff hold more liberal views compared to family carers on a variety of factors including intimate relationships, decision making and privacy in relationships for people with ID (Evans et al., 2009). Pownall et al. (in press) found that mothers of people with ID expressed concerns regarding their offspring's vulnerability to abuse and their ability to make informed choices within sexual relationships. Hence these differences found in attitudes between staff and family members could be related to family members' concerns and motivations to keep their (adult) child safe. Staff were found to hold greater support for people with mild, moderate or severe ID engaging in non-intimate relationships as opposed to sexual relationships. Previous studies have reported high prevalence rates of abuse for this population of people (McCarthy, 1999). It is possible that the less supportive attitudes that staff were found to hold towards people with different levels of ID engaging in sexual relationships could reflect their concerns about individuals' vulnerability to sexual exploitation/abuse.

Staff's concerns on the safety and wellbeing of people with ID may also reflect their beliefs regarding their responsibility to intervene in service users' relationships (Grieve et al., 2008). Thus, it is possible that these views could impact on the information and support that people with ID receive (Ward et al., 2001). If this was the case, the results from Gilmore & Chambers (2010) study would indicate that staff may be less willing to support the sexual

freedom of women with an ID, as they held less liberal attitudes to women on this topic. This is important to understand as a person's sexuality has been linked to their emotional wellbeing. Furthermore due to issues of social exclusion, individuals with ID are more likely to rely on staff for support with their personal lives (Forrester-Jones et al., 2006) and people with ID have stated that they value the support that staff provide them on sexual issues (Morrison, 2007). The Theory of Reasoned Action (Fishbein & Ajzen, 1975) and the Theory of Planned Behaviour (Ajzen, 1991) both state that attitudes impact on a person's behaviour. Thus, the less liberal or accepting attitudes that staff were found to hold towards people with an ID regarding parenting, homosexuality and women's sexual freedom, could impact on the support that staff provide service users on such issues. Consequently, it is not only important that we understand staff's attitudes to service users' sexuality, but it is also vital that insight is gained on how staff's attitudes impact on their willingness to support service users' sexual needs. Further research could be carried out exploring staff's role in supporting the sexuality of people with ID.

Limitations

The results of this review have to be considered within the methodological limitations discussed in relation to the studies. Moreover, it is also important to bear in mind that attitude research is particularly vulnerable to social desirability biases. Only one study (Bazzo et al., 2007) discussed this issue, and none of the studies included in this review reported steps that they had taken to reduce social desirability responses. Consequently, it should be noted that the liberal views expressed may not be a true reflection of all respondents' attitudes.

In conclusion, it is heartening to find that more accepting attitudes are being expressed by support staff regarding the sexuality of the people they work with. Nevertheless, this review also found that less liberal attitudes are still held towards particular issues, for example towards sexual freedom for women with ID. This highlights the need for better staff training and support to balance the competing roles of avoiding risk while at the same time trying to promote individuals sexual needs. With regards to the liberal attitudes that have been expressed by staff, there is no evidence indicating that such views result in a greater willingness to actually support individuals with their sexual matters. Examining the link between staff's attitudes and their support practice in relation to the sexuality of individuals with ID is the next step for research in this field.

References

Ager A., Myers F., Kerr P., Myles, S. & Green, A. (2001) Moving home: social integration for adults with intellectual disabilities resettling into community provision. *Journal of Applied Research in Intellectual Disabilities,* **14 (4)**, 392 – 400.

Ailey S.H., Marks B.A., Crisp C., Hahn J.E. (2003) Promoting sexuality across the life span for individuals with developmental disabilities. *Nursing Clinics of North America* **38 (2)**, 229 – 259.

Altman D.G., Schulz K.F., Moher D., Egger M., Davidoff F., Elbourne D., Gøtzsche

P.C. & Lang T. (2001) The revised consort statement for reporting randomized trials:

explanation and elaboration. *Annals of Internal Medicine* **134**, 663-694.

Ajzen I. (1991) The theory of planned behaviour. *Organizational Behavior and Human Decision Processes* **50 (2)**, 179 – 211.

Bazzo G., Nota L., Soresi S., Ferran L. & Minnes P. (2007) Attitudes of social service providers towards the sexuality of individuals with intellectual disability. *Journal of Applied Research in Intellectual Disabilities* **20 (2)**, 110 – 115.

Brantlinger E.A. (1983) Measuring variation and change in attitudes of residential care staff towards the sexuality of mentally retarded persons. *Mental Retardation* **21 (1)**, 17 – 22.

Brantlinger E.A. (1992) Professionals' attitudes towards the sterilisation of people with disabilities. *Journal of the Association for Persons with Severe Handicaps* **17 (1)**, 4 – 18.

Chapman J.W. & Pitceathly A.S. (1985) Sexuality and mentally handicapped people: issues of sex education, marriage, parenthood and care staff attitudes. *Australian and New Zealand Journal of Developmental Disabilities* **11 (4)**, 227 – 235.

Christian L.A., Stinson J. & Dotson L.A. (2001) Staff values regarding the sexual expression of women with developmental disabilities. *Sexuality and Disability* **19 (4)**, 283 – 291.

Craft A. & Craft M. (1981) Sexuality and mental handicap: a review. *The British Journal of Psychiatry* **139**, 494 – 505.

Critical Appraisal Skills Programme (2006) http:// www.casp.birmingham.org

Cuskelly M. & Bryde R. (2004) Attitudes towards the sexuality of adults with an intellectual disability: parents, support staff and a community sample. *Journal of Intellectual and Developmental Disability* **29 (3)**, 255 – 264.

Cuskelly M. & Gilmore L. (2007) Attitudes to sexuality questionnaire (individuals with an intellectual disability): scale development and community norms. *Journal of Intellectual and Developmental Disability* **32 (3)**, 214 – 221.

Drummond E. (2006) Attitudes towards sexuality: a pilot study in Ireland. *Learning Disability Practice* **9 (4)**, 28 – 34.

Evans D.S., McGuire B.E., Healy E. & Carley S.N. (2009) Sexuality and personal relationships for people with an intellectual disability. Part II: staff and family carer perspectives. *Journal of Intellectual Disability Research* **53 (11)**, 913 – 921.

Fishbein M. & Ajzen I. (1975) Belief, attitude, intention and behaviour: An introduction to theory and research. Addison-Wesley, Reading, MA.

Fischer H.L., Krajicek M.J. & Borthick W.A. (1973) Sex education for the developmentally disabled: a guide for parents, teachers and professionals. University Park Press, Baltimore. As cited in Cuskelly M. & Bryde R. (2004) Attitudes towards the sexuality of adults with an

intellectual disability: parents, support staff and a community sample. *Journal of Intellectual and Developmental Disability* **29 (3)**, 255 – 264.

Forrester-Jones R., Carpenter J., Coolen-Schrijner P., Cambridge P., Tate, A., Beecham J., Hallam, A., Knapp, M. & Wooff, D. (2006) The social networks of people with intellectual disability living in the community 12 years after resettlement from long-stay hospitals. *Journal of Applied Research in Intellectual Disabilities,* **19 (4),** 285-295.

Garbutt R. (2008) Sex and relationships for people with learning disabilities: a challenge for parents and professionals. *Mental Health and Learning Disabilities Research and Practice* **5**, 266-277.

Gilmore L. & Chambers B. (2010) Intellectual disability and sexuality: attitudes of disability support staff and leisure industry employees. *Journal of Intellectual and Developmental Disability* **35 (1)**, 22 – 28.

Grieve A., McLaren S., Lindsay, W. & Culling, E. (2008) Staff attitudes towards the sexuality of people with learning disabilities: a comparison of different professional groups and residential facilities. *British Journal of Learning Disabilities* **37**, 76 – 84.

International Classifications of Diseases and Related Health Problems (1992) 10th revision: ICD-10. World Health Organisation, Geneva.

Karellou J. (2003) Laypeople's attitudes towards the sexuality of people with learning disabilities in Greece. *Sexuality and Disability* **21(1)**, 65 – 84.

Lunsky Y. & Konstantareas M.M. (1998) The attitudes of individuals with autism and mental retardation towards sexuality. *Education and Training in Mental Retardation and Developmental Disabilities* **33**, 24 – 33.

McCabe M.P. (1999) Sexual knowledge, experience and feelings among people with disability. *Sexuality and Disability* **17 (2)**, 157 – 170.

McCarthy M. (1999) Sexuality and Women with Learning Disabilities. Jessica Kingsley Publishers, London.

McCarthy M. & Thompson D. (1997) A prevalence study of sexual abuse of adults with intellectual disabilities referred for sex education. *Journal of Applied Research in Intellectual Disabilities* **10 (2)**, 105 – 124.

Mitchell L., Doctor R.M. & Butler D.C. (1978) Attitudes of caretakers towards the sexual behaviour of mentally retarded persons. *American Journal of Mental Deficiency* **83 (3)**, 289 – 296.

Morrison, C. (2007). *Draft Report: People Should Tell You Stuff*. A report from the TASC Agency on a consultation finding out more about what young people with a learning disability need when it comes to sexual health services. NHS Health Scotland. Available at: http://www.healthscotland.com/uploads/documents/3289-Final%20DRAFT%20Full%20Report%20People%20should%20tell%20you%20stuff.pdf (accessed 20th July 2011).

Mulhern T. J. (1975) Survey of reported sexual behaviour and policies characterizing residential facilities for retarded citizens. *American Journal of Mental Deficiency* **79 (6)**, 670 – 673.

Murray J.L. & Minnes P.M. (1994) Staff attitudes towards the sexuality of persons with intellectual disabilities. *Australian and New Zealand Journal of Developmental Disabilities* **19 (1)**, 45 – 52.

Oliver M.N., Anthony A., Leimkuhl T.T. & Skillman G.D. (2002) Attitudes toward acceptable socio-sexual behaviours for persons with mental retardation: implications for normalisation and community integration. *Education and Training in Mental Retardation and Developmental Disabilities* **37(2)**, 193 – 201.

Oxford Essential English Dictionary (2011). University Press, Oxford.

Parsons G.E. (1982) Sexuality and mental retardation: a survey of attitudes and an analysis of the sexual behaviour or retarded people. Unpublished master's thesis, University of Queensland, Brisbane, Australia. As cited in Cuskelly M. & Bryde R. (2004) Attitudes towards the sexuality of adults with an intellectual disability: parents, support staff and a community sample. *Journal of Intellectual and Developmental Disability* **29 (3)**, 255 – 264.

Pownall J.D. (2010) Health knowledge and expected outcomes of risky behaviour: a comparative study of non-disabled adolescents and young people with intellectual and physical disabilities. Unpublished PhD.

Pownall J.D., Jahoda, A. & Hastings, R. (In press) Sexuality and sex education of adolescents with intellectual disabilities: mothers' attitudes, experiences, and support needs. Submitted to *Journal of Intellectual and Developmental Disabilities*.

Rose J. & Holmes S. (1991) Changing staff attitudes to the sexuality of people with mental handicaps: an evaluation of one and three day workshops. *Mental Handicap Research* **4 (1)**, 67 – 79.

Sweyn-Harvey R. (1984) Care staff attitudes. *Mental Handicap* **12**, 28 – 29.

The Adults with Incapacity (Scotland) Act (2000) Scottish Government.

Valuing people: a new strategy for learning disability for the 21st century (2001) Department of Health. HMSO, London.

Ward K.M., Trigler J.S. & Pfeiffer K.T (2001) Community services, issues and service gaps for individuals with developmental disabilities who exhibit inappropriate sexual behaviours. *Mental Retardation* **39 (1)**, 11 – 19.

Wish J.R., McCombs K.F. & Edmonson B. (1980) *The Socio-Sexual Knowledge and Attitudes Test*. Wood Dale: Stoelting. As referenced in Oliver M.N., Anthony A., Leimkuhl T.T. & Skillman G.D. (2002) Attitudes toward acceptable socio-sexual behaviours for persons with mental retardation: implications for normalisation and community integration. *Education and Training in Mental Retardation and Developmental Disabilities* **37(2)**, 193 – 201.

Chapter 2: Major Research Project

Investigating staff's attitudes and willingness to support men and women with mild intellectual disabilities on matters relating to their sexuality

Author: Andrea Gallagher*[1]

Mental Health and Wellbeing, University of Glasgow*

Address for Correspondence[1]

University of Glasgow

Mental Health and Wellbeing

Gartnavel Royal Hospital

1055 Great Western Road

Glasgow

G12 0XH

Tel: 0141 211 3920

Fax: 0141 211 0356

Email: a.gallagher.1@research.gla.ac.uk

KEYWORDS: intellectual disability, attitudes, willingness, support, staff, sexuality

Submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology (D. Clin. Psy.)

Prepared in accordance with requirements for submission to: *Journal of Intellectual Disability Research (Appendix A)*

Lay Summary

A person's sexuality, that is, their sexual identity and the way they choose to express themselves in sexual relationships, is linked to their wellbeing. In the past, negative attitudes were generally held towards the sexuality of people with intellectual disabilities by the staff that supported them. Over the years, these attitudes have become more accepting. We wanted to get an up to date understanding about support staff's attitudes towards sexuality in men and women with an intellectual disability. We also wanted to find out if staff's attitudes were linked to how willing they are to support the people they work with on sexual matters, such as sex education or developing relationships. We used a questionnaire and an interview with staff to gather this information. We found out that staff had liberal attitudes to the sexuality of people with intellectual disabilities, and no significant differences were found on their attitudes to men compared to women. We also learned that most staff wanted to support the sexuality of the people they worked with, and that their positive attitudes were linked to their willingness to offer help. This is important to learn, as people with intellectual disabilities rely on staff for support with their sexuality. More is needed to help staff to openly offer support, so that people with intellectual disabilities get the assistance they deserve.

Abstract

Background

This study explored residential support staff's attitudes towards sexuality in men and women with an intellectual disability (ID), and whether their attitudes were linked to a willingness to support service users with sexual matters.

Method

The Attitudes to Sexuality Questionnaire - Individuals with an Intellectual Disability was used to gather data on 34 support staff's attitudes. This was supplemented with additional questions on risk issues developed by the author. A semi-structured interview examined staff's experiences of supporting sexual matters.

Results

Liberal attitudes were held, no statistically significant differences were found on attitudes to men and women. Nonetheless, trends were found with more liberal views expressed about men than women on sexual rights and non-reproductive sexual behaviour. Most staff were willing to support the sexuality of service users. A positive association was found between staff's attitudes and their willingness to support sexuality. Willingness was not associated with feelings of confidence or comfort in dealing with sexual matters.

Conclusions

Sexuality is an integral aspect of quality of life. Understanding staff's values and attitudes towards the sexuality of people with ID is important, as this population of people rely on staff for support on this sensitive topic. Assisting the sexuality of people with ID is a complex and emotive subject worthy of further investigation.

Introduction

The term sexuality can be used to describe how people identify and express themselves through intimate relationships and sexual practice (Dunn, 2001), and is critical to psychological wellbeing (Ailey et al., 2003). Nonetheless sexuality has been a contentious issue for people with intellectual disabilities (ID). Historically they tended to be viewed through sexual stereotypes, possibly still prevalent, as either asexual, 'the eternal child' or being promiscuous (McCarthy, 1999). Philosophies such as normalisation have had some impact on the service provision and the quality of life for people with ID. Nevertheless, this population of people can still face challenges with regards to their sexuality and relationships (Brown, 1994). One of the challenges is that many people with an ID rely on carers for support with their sexuality, for instance in developing relationships. Unfortunately, staff have reported concerns about being able to offer support on sex and relationships to the service users they work with (Abbot and Howarth, 2007).

Support staff and the organisations they work in have a crucial role in the lives of people with ID. Pownall (2010) found that young people with ID were less likely to discuss sexual issues with their peers than young people without disabilities. In addition, formal sex education frequently failed to sufficiently address their information needs. Having fewer routes to learning about sexual matters than their non-disabled peers may mean that individuals with ID are more reliant upon staff taking an active role in supporting them on this sensitive topic. Nonetheless, previous research has found that staff do not receive adequate training or have access to guidelines on how to support sexuality for people with ID (Ward et al., 2001). Additionally, staff who had not received training on supporting sexuality reported varying opinions on the assistance they believed they should offer service users and

what constitutes acceptable sexual behaviours for people with ID (Ward et al., 2001). Without appropriate training, staff may be forced to rely on their personal beliefs regarding sexuality and disability to guide their support practice. Consequently, it is important to obtain an up to date understanding of support staff's attitudes, their willingness to help people with ID with sexual matters and the factors that may impact on such attitudes and support.

The literature exploring staff's attitudes to sexuality has measured whether staff hold liberal attitudes on this subject. A liberal attitude has been defined as a way of thinking which is tolerant or open minded (Oxford English Dictionary, 2011). The instruments developed to investigate staff's attitudes to sexual matters, for example the Attitudes to Sexuality Questionnaire – Individuals with an Intellectual Disability (ASQ-ID; Cuskelly & Gilmore, 2007), have measured whether staff hold accepting or positive attitudes. For example, staff who express accepting attitudes towards sexual matters for people with ID might be expected to be supportive of people with ID making informed choices about their sexuality and having opportunities to develop sexual relationships. Research exploring support staff's attitudes towards sexuality has found that more liberal views are associated with several factors, including higher professional qualifications (Murray & Minnes, 1994), receiving training on sexuality for people with ID (Rose & Holmes, 1991), being younger (Murray & Minnes, 1994; Cuskelly & Bryde, 2004), holding religious views (Ryan & McConkey, 2000), and working within small community based settings (Grieve et al., 2008). More recent studies have found that age does not necessarily impact on attitudes (Gilmore & Chambers, 2010). These contradictory findings about age may simply reflect the development of more liberal attitudes towards the sexuality of people with ID held across the population of support staff in recent years.

A service user's vulnerability and gender may also influence staff's attitudes towards their sexuality (Grieve et al., 2008). Gilmore & Chambers (2010) measured support staff's and leisure staff's attitudes using Cuskelly & Gilmore's (2007) modified version of the Attitudes to Sexuality Questionnaire - Individuals with an Intellectual Disability (ASQ-ID; Cuskelly & Bryde, 2004). Staff believed that men with ID had less control over their sexual feelings than women with ID. Moreover, staff were less accepting of sexual freedom for women with ID compared to typically developing women. This could imply that staff members were less willing to provide information about sexual matters to women or were less willing to support their sexual expression. Also relevant here is staff's awareness of the vulnerability of people with ID to exploitation and abuse (Garbutt, 2008). Unfortunately, the ASQ-ID has only one question which investigates attitudes relating to risk issues. It is possible that adding further questions to explore risk/vulnerability issues may provide more insight into staff's attitudes on this topic.

Differences in staff's attitudes to the sexuality of men and women with ID could reflect real concerns, as women are more vulnerable than men to exploitation/abuse (McCarthy, 1999). Research indicates that the incidence of sexual abuse towards women with ID is particularly high (Millard, 1994, McCarthy and Thompson, 1997). McCarthy (1996) reviewed the people with ID referred to a sex education support service and found that the most common reason for referrals was due to staff's concerns that the women they supported were sexually vulnerable. Significantly fewer men were referred due to concerns about their sexual vulnerability. Instead, men were more often referred due to their sexually abusive behaviour which was frequently towards other women with ID. Due to such risk factors it is possible that staff may err on the side of caution and adopt a protective role in the support they offer. This indicates that attitudes to sexuality in general may not be the only factor influencing

staff's support behaviour, and other contextual issues such as risk/vulnerability matters could also play a role.

There is limited research examining the assistance staff offer to people with ID for sexual matters. Abbott and Howarth (2007) explored staff's support behaviour in assisting people with ID who are homosexual or bi-sexual and found that staff were avoidant, or at best reactive, in providing support for sexual matters. Staff in this study reported that a lack of training and policies on assisting sexual matters was a barrier to them offering support on this topic. A number of studies have reported that adequate training and clear policy guidelines are required to assist staff in this support role (McConkey & Ryan, 2001; Rose & Holmes, 1991). Whilst organisations may have such policies, it has been reported that staff can be unsure about their content or how to implement them when sexual matters arise (Grieve et al., 2008). If staff do not have clear guidance about their role in supporting sexuality, it might be reasonable to suppose that their support practice is more likely to be influenced by their own attitudes.

The theory of planned behaviour (TPB; Ajzen, 1991) suggests that attitudes are linked to behaviour; however, there is not a direct association. Also important is a person's perceived behavioural control, which is their perception of the ease or difficulty of carrying out a behaviour. This in turn affects the formation of behavioural intentions which impacts on behaviour itself. This has often been related to the concept of self-efficacy (Armitage & Conner, 2001). Thus, though the link between staff's attitudes and their support practice is important to explore, it would be wrong to assume that attitudes alone reflect how support is delivered to people with ID. For example, staff's feelings of confidence have been linked to

prior experience of supporting sexual matters and a belief that support will be offered in the future (McConkey & Ryan, 2001). This signifies that other factors which could impact on staff's support practice should be considered.

In an attempt to broaden the literature this study investigated not only staff's attitudes to sexuality but also their willingness to support service users with sexual matters based on their real life experiences of providing support. Gender has been considered to be an important construct influencing staff's attitudes and has been linked to concerns regarding service users' vulnerability (McCarthy, 1999). Hence, gender was explored with respect to attitudes and willingness to offer support for sexual matters. In particular, female service users' vulnerability to sexual abuse/exploitation could be a source of concern influencing staff's attitudes (Gilmore & Chambers, 2010), and questions on risk issues were used to explore this topic. Finally the association between staff's attitudes, their willingness to support sexuality and their feelings of confidence and comfort to do so was also examined.

Research Hypotheses

1. Staff will hold less liberal attitudes towards the sexual needs of women compared to men with ID. Gender differences in attitudes will be found with regard to risk /vulnerability factors.

2. More liberal attitudes will be associated with a greater willingness to support service user's sexual needs.

3. Staff's willingness to provide support with sexual matters will be positively associated with their feelings of confidence and comfort regarding this subject.

Method

Participants

Thirty four female support workers were recruited to this study (mean age 40.09 yrs) from five residential support services for people with ID in the West of Scotland. Participants had worked in their current post for an average of 5 years. Thirteen participants had high school qualifications while 21 had gone onto further education. Twelve participants had received training on supporting service users with sexual matters, and all but one participant stated they would like further training on this topic. The most frequent type of training that the participants wanted was on how to talk to service users or educate them about sex and relationships (n = 14). Details of participant characteristics are summarised in Table 1.

Table 1: Participant characteristics (N = 34)

Age (yrs)	**Mean**: 40.09, **SD**: 11.54, **Range**: 19 – 62	
Religious Affiliation	**No religion**: 14 (41.2%)	
	Catholic: 11 (32.4%)	**Practising**: 4 (36%) **Not Practising**: 7 (64%)
	Protestant: 5 (14.7%)	**Practising**: 3 (60%) **Not Practising**: 2 (40%)
	Christian: 4 (11.8%)	**Practising**: 2 (50%) **Not Practising**: 2 (50%)
Level of qualification	**School**: 13 (38.2%), **College**: 17 (50%), **University**: 4 (11.8)	
Total time working in ID services (months)	**Mean**: 124.35, **SD**: 94.77, **Range**: 7 – 420	
Time working in current service (months)	**Mean**: 63.74, **SD**: 51.71, **Range**: 5 – 216	
Received training on supporting sexual matters	**Yes**: 12 (35.3%) **No**: 22 (64.7%)	
Would like to receive (further) training on supporting sexual matters	**Yes**: 33 (97.1%) **No**: 1 (2.9%)	

Further training request*:	
1. Educating/talking about sex/relationships	14 (41.2%)
2. Staff's roles/responsibilities on supporting sexual matters	9 (26.5%)
3. Resources	6 (17.6%)
4. Legal issues/capacity	11 (32.4%)
5. Nothing Specific	8 (23.5%)
6. Reducing barriers to service users accessing support	2 (5.9%)
7. Providing emotional support	1(2.95%)
8. Pregnancy	1 (2.95)

*Some participants requested more than one training topic

Inclusion Criteria: i) Participants needed to have at least five months experience of work. This was to ensure that they had time to build a trusting relationship with service users and thereby facilitate discussions about sensitive issues such as sexual matters. ii) Participants had to support service users who had sufficient communication abilities, to be able to express their views and have some comprehension of what staff were saying to them. This was determined using items from the Adaptive Behavour Scale (ABS – RC: 2; Nihira et al., 1993) to ask whether the target individuals that participants discussed supporting had the ability to: a) talk to others about sports, family, group activities, etc, b) sometimes use complex sentences containing 'because', 'but', etc, c) answer simple questions such as 'what is your name?' or 'what are you doing?'. iii) Participants were required to be female support staff. This was due to the preponderance of female support staff within ID services making it challenging to recruit a balanced sample of males and females in the required time scale. iv) Participants had recently, or were currently, supporting a service user with sexual matters. Three participants were excluded from the study as they did not meet inclusion criteria.

Exclusion Criteria: Participants who worked in residential settings where there had been recent incidents or accusations of sexual assault which were unresolved were excluded from this study.

Materials

The following materials were used: background information sheets, semi-structured interviews and attitudes questionnaires. The questionnaires and interview were administered with each participant in the order that they are presented below.

1. Participant background information sheet

This was used to collect socio-demographic information on the participants' age, religion, time working in ID services, and training and awareness of policies on supporting people with ID with their sexuality. A copy of the background information sheet can be found in Appendix B.

2. Semi-structured interview

A semi-structured interview was developed by the researcher to gather information about participants' real life experiences of supporting service user's sexuality, while specifically exploring their willingness to provide support on sexual matters. The interview was developed based on previous research by Pownall et al. (2011) who explored mothers' experiences of supporting their offspring with regard to their developing sexuality. The aim was to develop a dialogue with the participants so that they would feel comfortable discussing their recent/last experience of supporting sexual matters. Hence, open questions were used, initially asking the participants to explain how they became aware that a service user required support. Using this approach the following topics were covered: a) the sexual matters that required support, b) how they responded, c) feelings of comfort and confidence, d) if they would do anything differently in the future, e) the support that was available for

them to assist them in carrying out their role, and finally f) their overall reflection on the support they provided. Although a topic guide was used to ensure that key questions were addressed, the order in which the topics were discussed was not imposed by the researcher. Likert scales developed by Pownall et al. (in press) were used to obtain participants' ratings of confidence and comfort regarding the support they provided. A copy of the semi-structured interview can be found in Appendix C.

The semi structured interview was piloted with the first six participants recruited to examine whether the format used allowed the necessary topics to be addressed. Piloting assisted in developing strategies for introducing the interview, to allow the participants to be put at ease and a natural flow of conversation to develop. The information gathered from the further 28 interviews remained the same as that gathered from participants involved in the pilot. As a result individuals who took part in piloting were included in the study.

3. Attitudes to sexuality questionnaire

The Attitudes to Sexuality Questionnaire - Individuals with an Intellectual Disability (ASQ-ID; Cuskelly & Bryde, 2004) has high test-retest reliability ($r = 0.91$) and good internal consistency (Cronbach's alpha > 0.90). Cuskelly & Gilmore (2007) modified this questionnaire, dividing it into two sections to measure attitudes towards sexuality in men separately from attitudes towards sexuality in women. A factor analysis revealed four subscales; Sexual Rights (13 items, e.g. discussions on sexual intercourse promote promiscuity in women/men with ID), Parenting (7 items, e.g. with the right support women/men with ID can rear well adjusted children), Non-Reproductive Sexual Behaviour (5

items, e.g. consenting adult women/men with ID should be allowed to be in a homosexual relationship if they so desire) and Self-Control (3 items, e.g. women/men with ID have stronger sexual feelings than other women/men). Participants were instructed to answer with respect to people who had a similar level of ability as the individuals discussed in the semi-structured interview. Questions were answered on a Likert scale ranging from strongly disagree to strongly agree. Higher scores indicate more liberal attitudes, or more positive and accepting attitudes, towards the sexuality of people with ID. As the ASQ-ID had only one question on risk/vulnerability, a further 4 questions exploring these issues were added. Risk questions were developed based on the literature discussing the vulnerability of people with ID, specifically women, to sexual exploitation (McCarthy, 1999). Questions explored staff's opinions regarding this vulnerability and whether they considered their role to involve protecting the service users' they work with. A copy of the questionnaire is available in Appendix D.

Research Procedure

Ethical approval (Appendix E) was obtained from University of Glasgow Medical Faculty Ethics Committee. Initial recruitment involved delivering presentations about the research project to staff groups in their place of work. During presentations information packs containing a consent form (Appendix F), covering letter (Appendix G) and information sheet (Appendix H) were disseminated. Those individuals who volunteered to take part in the study were contacted to arrange an appointment at their place of work. Upon meeting the researcher in a private interview room participants were again briefed on the purpose and process of the study and asked to sign a consent form if they had not already done so. Participants completed all measures face to face with the researcher in one session which

lasted approximately 30 – 50 minutes. With participants' permission answers were anonymously recorded on the measures and using digital recording equipment. A flow chart detailing the recruitment process can be found in Appendix I.

Sample size

Required sample size was determined based upon previous research examining staff attitudes towards the sexuality of men and women. Using the ASQ-ID Gilmore & Chambers (2010) found a significant difference in attitudes towards men and women's self control, with a small/medium effect size (0.3). As this study added questions exploring attitudes towards vulnerability/risk issues it was anticipated that a medium effect size would be found. Based on an effect size of 0.5, with an alpha level of 0.05 and a power of 0.8 (two tailed) the estimated sample size for this study was 34 (G*Power 3, Faul et al., 2007).

Results

The first section of the results discusses data from the semi-structured interviews on staff's experiences of supporting sexual matters, including the development of a coding framework. The second section outlines the outcome of normality testing and reliability testing on the attitude questionnaire with the final section addressing the results from the research hypotheses.

Development of Content Analysis Coding Framework for Semi-Structured Interviews

Coding of participants' willingness to support sexual matters was initially based on research by Abbott and Howarth (2007), McCarthy (1999) and Millard (1994), whereby initial willingness categories of 'Restrictive', 'Ignoring/Avoidant', 'Reactive' and 'Proactive' were identified. Based on this literature directed content analysis (Hsieh & Shannon, 2005) of the interviews was carried out and attempts were made to use the initial four categories of willingness as a framework. Unlike the results found by Abbott and Howarth (2007) this study did not find evidence to code participants' support practices as 'Ignoring/Avoidant' or 'Proactive'. Instead the categories found to fit the participants' responses were 'Restrictive', 'Reactive' and 'Reactive and Open'. In addition, content analysis categories were developed regarding i) the type of sexual matters which required support, ii) the support that was provided by participants, and finally iii) if participants would do anything differently in the future. Relevant interview sections relating to participants' responses to particular questions were transcribed verbatim and coded from the transcripts. The final categories are described in the following sections and illustrated with quotes. Definitions for each category can be found in Table 2 below.

Table 2

Category: Willingness to support sexual matters	**Definition of the category**
Restrictive	Participants described using support practices which deliberately restricted the sexuality of the service user.
Reactive	Participants responded to the service user's request for assistance with sexual matters/ noted that assistance was required with sexual matters and provided some support.
Reactive and Open	Participants responded to the service user's request for assistance with sexual matters/noted that assistance was required with sexual matters and provided some support. Participants in this category also attempted to find additional means to support service user's sexuality.

Category: sexual matters raised which required support	**Definition of the category**
Education Issues: personal safety/acceptable behaviour in relationships/boundaries	The service user's lack of knowledge about acceptable behaviour and safety within relationships required support.
Education Issues: sex education	The service users lack of knowledge on sexual matters required support.
Education Issues: emotional impact of parenting	The service user appeared to require knowledge on how emotionally challenging parenting could be.
Developing Relationships	Support issues raised regarding the service user forming a relationship or their relationship developing.
Risk issues	Issues regarding service user's vulnerability were raised, or the service user raised allegations of abuse and support was given in relation to such issues.
Inappropriate Behaviour	Issues regarding a service user's inappropriate behaviour were identified.
Sexual Health Matters	The service user required support on matters relating to sexual health issues.
Category: Support offered	**Definition of the category**
Accessed information or resources for service users	Staff supported service users by providing them with information or resources/services which assisted in their support with sexual matters.
Supported the service user to develop relationships	Staff offered physical support to the service user, or helped them to socialise, to assist them with developing their relationships.
Spoke to relevant others	Staff spoke to staff, family members or other professionals to clarify the situation, and/or contacted relevant professionals to access further support or information.
Talked to the service user	Staff spoke to the service user about the sexual matters raised, attempted to clarify the support need, offered advice/information/options.
Category: What the participants would do differently	**Definition of the category**
Would not do anything differently	Staff stated that they would not change the support that they offered
Obtain information/support for self and/or other staff	Staff explained that they would gain further information for themselves and/or other staff that would inform their practice

Obtain information/support for service user	Staff stated that they would gather more information for the service user or support the service user to access information or services.
Do not know	Staff were unsure whether they would offer different support in the future

Reliability of Coding Framework

The inter-rater reliability of the categories derived from the semi-structured interviews was ascertained. In total 36 quotes were co-rated, quotes being selected from seventeen categories across a sub-set of interviews. The two raters were the current author and Dr J. Pownall, who has significant research experience in this field and is familiar with using methods of content analysis. The Kappa statistic was used to assess for inter-rater agreement on the categories developed and was found to be Kappa = 0.91. Discrepancies were discussed and 100% agreement was obtained.

Descriptive Data from the Content Analysis of the Semi-Structured Interviews

Directed content analysis was carried out on 34 interviews. Most participants discussed their experiences of supporting women with sexual matters (n = 26). The main categories identified included a) the sexual matters that service users' required support with, b) the participant's willingness to offer support, c) the type of support offered, and d) if in retrospect, the participants would have done anything differently.

A. Sexual matters which required support

Five categories were identified; 'Education Issues' (n = 15), 'Developing Relationships' (n = 10), 'Risk Issues' (n = 8), 'Sexual Health Issues' (n = 4) and 'Inappropriate Behaviour' (n =

1). A number of the participants' support experiences fell into more than one category. Only female service users were supported with risk issues. Both male and female service users were most frequently supported with 'Education Issues', an example quote from this category is:

> "we found a pregnancy test in his bin....It's hard to get him engaged to find out what level he is at.....through conversations that we had it transpires that he doesn't actually, he's saying that he has never been sexually active, he doesn't actually know what a sexual act involves" (participant 32yrs, not received training, discussing supporting a male service user)

Further examples of quotes for each of the categories of sexual matters which required support can be found in Appendix J.

B. Willingness to support sexual matters

Three willingness categories were identified: 'Restrictive' (n = 2), 'Reactive' (n = 13) and 'Reactive and Open' (n = 19).

'Restrictive' (n = 2): Participants whose support practices restricted the sexuality of the service user were categorised as 'Restrictive'. One participant categorised as 'Restrictive' stated that she prevented opportunities for a female service user to be intimate with her partner at home as protocols were not established:

> "making sure that they weren't left in the room together and stuff, and if they were, cause we couldn't stop it either, just making sure that the door was open.... Obviously the sex thing came up as well, just kind of trying to, it's going to happen eventually but its trying to discourage it as well I think, to an extent anyway. I suppose it's a natural thing, you cant really stop them but its no for us to be like "on you go", we need protocols and stuff so we know what we are doing" (participant 27yrs, no training on supporting sexual matters, discussing supporting a female service user).

'Reactive' (n = 13): Participants who responded to the service user's request for assistance with sexual matters or noticed that assistance was required and provided support were categorised as 'Reactive'. Participants described supporting two men and eleven women in this way. The most frequent sexual matter that received support from participants categorised as 'Reactive' was on 'Education Issues' (n = 5), followed by 'Developing Relationships' (n = 4), 'Risk Issues' (n = 2), and 'Sexual Health Issues' (n = 2). Support was given directly to the service user or indirectly by notifying relevant others that support needs were present. The following quote illustrates an example of this category:

> "She sees things on the telly then she thinks she is pregnant.... We still need to take her up to the doctors every day for a pregnancy test cause she's asked us to support her with that." (participant 33yrs, received training, discussing supporting a female service user).

'Reactive and Open' (n = 19): Participants whose support practices were categorised as 'Reactive and Open' were initially like those categorised as 'Reactive'; they responded to service users' request for assistance or offered supported when they recognised that it was needed. However, participants in this category also attempted to find additional means to support service users' sexuality. Participants supported six men and thirteen women using this approach. The most frequent sexual matter that service users were supported with by participants categorised as 'Reactive and Open' was 'Education Issues' (n = 10), followed by 'Risk Issues' (n = 5), 'Developing Relationships' (n = 5), 'Sexual Health Issues' (n = 2), and 'Inappropriate Behaviour' (n = 1). Some support experiences fell into more than one category. An example quote from this category is:

> "Every time that she did go out and come back and say that she had been with someone we always took her to the (sexual health clinic) to check and see if she was okay and see if she had caught any disease....explaining to her.... that it was safer to get her checked out....it was always me that took her.... We thought that it would be good for the individual to have someone there and promote quite a good relationship....suggested to the female if she would like to go out for a meal with this male during the week....tried quite a lot to encourage her to invite him over to the flat to have dinner but it never materialised." (participant 43yrs, not received training, discussing supporting a female service user).

Further examples of quotes from each of the willingness categories can be found in Appendix J. Table 3 outlines the frequency of the willingness categories in relation to the type of sexual matter that required support and gender of the service user receiving support.

Table 3: Type of sexual matter requiring support, willingness category and gender of service user receiving support

Willingness category	**Frequency of staff in willingness category**	**Type of sexual matter requiring support***	**Gender of the service user requiring support**	
			Men	Women
'Reactive'	N: 13 (38.2%)	'Education Issues':		
		Personal safety / acceptable behaviour in relationships / boundaries	1	1
		Sex education	0	1
		Emotional impact of parenting	0	2
		'Developing Relationships'	1	3
		'Risk Issues'	0	2
		'Sexual Health Issues':	0	2
		Pregnancy testing		
'Reactive and Open'	N: 19 (55.9%)	'Education Issues':		
		Personal safety/acceptable behaviour in relationships / boundaries	1	4
		Sex education	2	3
		'Developing Relationships'	2	3
		'Risk Issues'	0	5
		'Inappropriate Behaviour'	1	0
		'Sexual Health Issues':		
		Smear testing	0	1
		STD testing	0	1
'Restrictive'	N: 2 (5.9%)	'Relationships'	0	1
		'Risk Issues'	0	1

* Due to the nature of the sexual matters supported, some participant's support experiences fell into more than one category

C. Support offered

The support that participants offered service users fell into four categories, each category had two sub-categories, a number of participants offered more than one type of support:

i) 'Talked to the Service User' (n = 32) had two subcategories of A) providing the service user with information or advice on sexual matters (n = 20) and B) attempting to clarify the service users' support needs (n = 12).

ii) 'Spoke to Relevant Others' to clarify the situation or access further information (n = 23) was split into subcategories of A) speaking with staff or family members (n = 10), and B) speaking with other professionals (n = 13).

iii) 'Supported the Service user to Develop Relationships' (n = 5) was categorised further as A) supporting the service user socially (n = 4), and B) supporting the service user physically (n = 1).

iv) 'Accessed Information or Resources' (n = 6) had two subcategories of A) accessing sexual health resources (n = 5), and B) accessing information on previous supports (n = 1).

As indicated the most frequent category of support offered was 'Talked to the Service User', an example of this category is:

> "I would explain to her 'do you realise what having a boyfriend is' and she said 'oh aye'...and I asked her if she knew what intercourse was, she didn't....I did speak to her in depth about it....I had to tell her, relationships have different levels....she was wanting her boyfriend at the time to stay over and I actually explained to her exactly what that could mean" (participant 52yrs, received training, discussing supporting a female service user)

Further example quotes on the support that participants offered service users are detailed in Appendix J.

D. What the participant would do differently

Participants were asked if they would offer different support in the future. Some participants' gave more than one response. Their answers fell into four categories: i) 'Obtain Information/Support for Self and/or Other Staff' (n = 12), ii) 'Obtain Information/Support for Service User' (n = 10), iii) 'Would Not Do Anything Differently' (n = 17), and iv) 'Do Not Know' (n = 1). An example quote from the most frequent category, 'Obtain Information/Support for Self and/or Other Staff' is:

> "I'd like to find out more information...if I was to attend a course then I could maybe deal with it myself and just say, explain to her a bit better about how do you get pregnant….If I had the experience, if she was to ask me questions then I wouldn't feel embarrassed I would know and I could just explain to her" (participant 33yrs, received training, discussing supporting a female service user).

Further example quotes on what the participants would do differently when offering support in the future can be found in Appendix J.

Normality Testing on Attitude Data and Reliability of Attitude Questionnaire

Tests of normality were carried using the Shapiro-Wilk statistic as the sample size was less than 50 (SPSS 14 Quick Guide, 2009). The ASQ-ID sexual rights subscale for women and the self-control subscale for men were normally distributed. Conversely the ASQ-ID total attitude scores, further subscale scores on parenting and non-reproductive sexual behaviour, and the risk questions added by this study were not normally distributed. Outliers were identified within box-plots, however, their removal did not change the outcome of analyses thus the original results from the analysis are reported. As the data was not found to be normally distributed Wilcoxon sign tests will be used to test for differences on the attitude data.

Cronbach's alpha coefficients were calculated for participants' attitudes scores. The risk questions were analysed separately due to poor item total correlations. With the risk questions removed the ASQ-ID had good internal consistency overall (alpha = 0.96) and for each subscale separately (sexual rights alpha = 0.90, parenting alpha = 0.89, non-reproductive sexual behaviour alpha = 0.84 and self control alpha = 0.81).

Quantitative Analysis

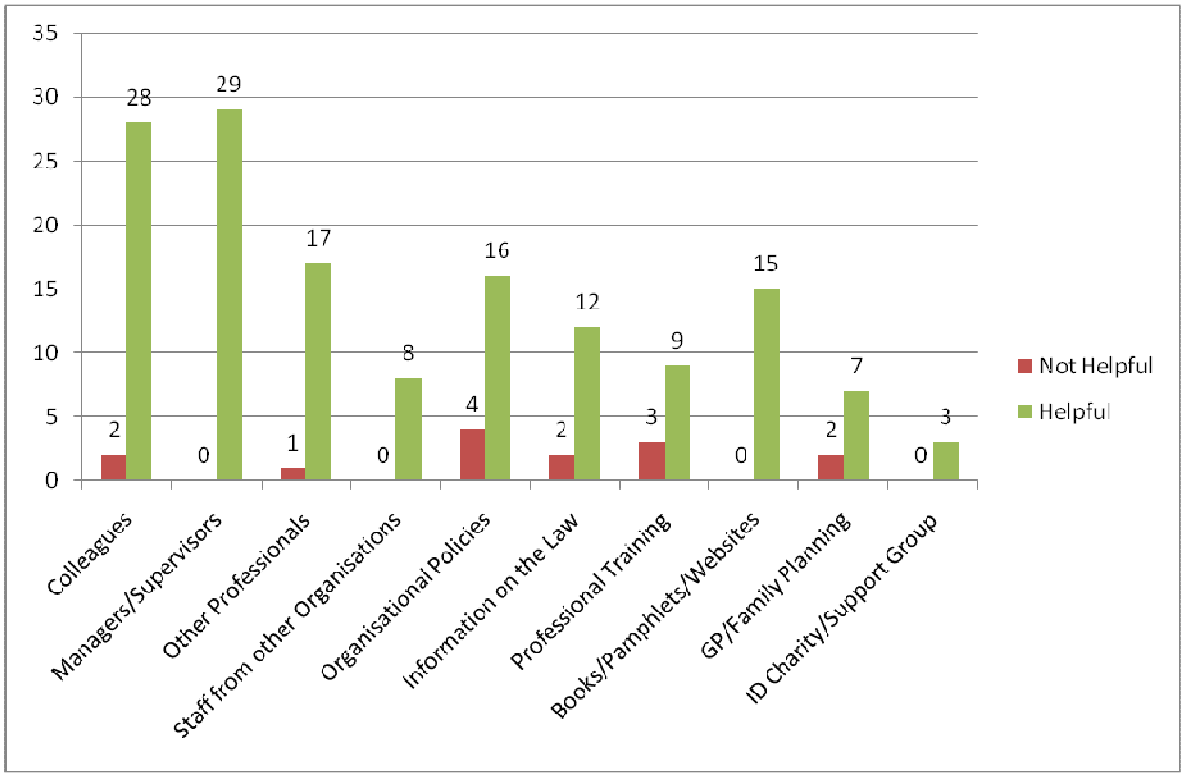
Descriptive quantitative data

The 34 participants who took part in this study rated their levels of confidence and comfort when providing the support for the sexual matters they discussed during the interviews. The most frequent rating for confidence was 'very' confident (n = 14). The most frequent rating of comfort was 'very' comfortable (n = 13). Eight participants discussed their experiences of supporting men with sexual matters, and 26 participants spoke about supporting women. During interviews participants were also asked about the assistance that they accessed for themselves to help them carry out their support role. Managers (n = 29) and colleagues (n = 28) were the sources of support most frequently reported by participants as being both available and helpful in assisting them with their role. More details on participants' feelings of confidence, comfort and the support available to them can be found in Table 4 and Graph 1 below

Table 4: Gender of the service user that participants discussed supporting, participants' ratings of confidence and comfort when providing support.

Most recent experience of supporting sexuality	Men: 8 (22.2%) Women: 26 (77.8%)
Feelings of Confidence	Not at all: 2 (5.9%) Slightly: 5 (14.7%) Generally: 12 (35.3%) Very: 14 (41.2%) Extremely: 1 (2.9%)
Feelings of Comfort	Not at all: 1 (2.9%) Slightly: 7 (20.6%) Generally: 12 (35.3%) Very: 13 (38.2%) Extremely: 1 (2.9%)

Graph 1 Illustrating the support that participants' accessed to assist them in carrying out their role and whether they found this support helpful.



The scores for the participants' attitudes to men on the ASQ-ID (median = 85) were similar to the attitude scores to women (median = 83.5). Further information concerning participants' attitude scores on the ASQ-ID subscales and risk questions are provided in table 5.

Table 5: Attitude Median Scores and Ranges

	Median and Range Attitudes to Men with ID	Median and Range Attitudes to Women with ID
ASQ-ID (possible range of scores: 0 – 112)	85 74 – 110	83.5 70 – 112
ASQ-ID Sexual Rights Subscale* (possible range of scores: 0 – 52)	39 33 – 52	38.5 31 - 52
ASQ-ID Non-Reproductive Sexual Behaviour Subscale* (possible range of scores: 0 – 20)	16 13 – 20	15 13 - 20
ASQ-ID Parenting Subscale (possible range of scores: 0 – 28)	21 12 – 26	21 14 - 28
ASQ-ID Self Control Subscale (possible range of scores: 0 – 12)	9 5 – 12	9 7 - 12
Risk Question 1 (possible range of scores: 0 – 4)	3 0 – 4	3 1 – 4
Risk Question 2 (possible range of scores: 0 – 4)	3 1 – 4	3 1 – 4
Risk Question 3 (possible range of scores: 0 – 4)	1 0 – 3	1 0 – 4
Risk Question 4 (possible range of scores: 0 – 4)	3 1 – 4	3 1 - 4

*Trends in differences found; ASQ-ID Higher scores = more liberal attitudes. Risk Q1: explores attitudes towards the risk of exploitation of men/women with ID compared to men/women without ID, higher scores = belief people with ID more at risk. Risk Q2: explores attitudes towards staff's role in protecting men or women with ID from sexual abuse/exploitation, higher scores = belief that staff have this role. Risk Q3: explores attitudes towards staff's role in protecting others from men or women with ID who are sexually active, higher scores = belief that staff do not have this role. Risk Q4: explores attitudes towards reducing men or woman's sexual freedom and the impact that would have on reducing their vulnerability to sexual abuse/exploitation, higher scores = belief that reducing sexual freedom does not ensure that vulnerability reduces.

Quantitative analysis of the research hypotheses

i) Staff will hold less liberal attitudes towards the sexual needs of women compared to men with ID. Differences in attitudes will be found with regard to risk/vulnerability factors (Hypothesis 1)

As multiple tests were carried out, the critical alpha value was reduced to 0.01. Using Wilcoxon sign tests no differences were found on participants attitudes to men compared to women on their overall score of the ASQ-ID, on subscales on parenting and self-control, or on the risk questions added by this study ($p > 0.01$). However, trends in differences were found; staff held more liberal attitudes towards the sexual rights and non-reproductive sexual behaviour for men with ID than women with ID ($z = -2.07$, $p = 0.02$, $r = 0.35$, and $z = -1.97$, $p = 0.03$, $r = 0.34$ respectively).

ii) More liberal attitudes will be associated with a greater willingness to support service users' sexual needs (Hypothesis 2)

A Chi-square test for independence was used to test for an association between participants' attitudes to sexuality and their willingness to support sexual matters. As some participants reported on their experiences of supporting men and some supporting women, the analysis examined this association with the measure of participants' attitudes to someone of the same gender. To meet the assumptions of Chi-square, only willingness categories of 'Reactive' and 'Reactive and Open' were used in the analysis. As the 'Restrictive' willingness category is quite distinct from the other willingness categories, it was not appropriate to collapse the 'Restrictive' into 'Reactive' or 'Reactive and Open' for this analysis. Interval data on attitudes was converted into two categories ('Liberal' and 'Very Liberal'). As all attitudes

scores were liberal, the median score (median = 83) was used to divide the data into these two categories. Therefore scores that ranged below the median were categorised as 'Liberal' and scores that ranged from 83 upwards were categorised as 'Very Liberal'. A significant association was found between attitudes and willingness to support sexual matters x^2 (1) = 5.78, $p < 0.05$, *phi* = 0.43. Regarding the participants whose willingness to support sexuality was categorised as 'Restrictive', one had an attitude score categorised as 'Liberal', with the other categorised as 'Very Liberal'.

Post hoc analysis (1)

As a significant result was found between attitudes and willingness, a binary logistic regression was performed to explore the association further, with attitudes as a continuous variable and willingness as a categorical variable. To meet the multicollinearity assumptions of logistic regression a Spearman's rho correlation was used to test for an association between participants' age and overall attitude scores. Medium negative correlations were found between age and attitudes to men, $r = -.36$, n = 34, $p < 0.05$, and age and attitudes to women, $r = -.41$, n = 34, $p < 0.05$. Consequently, age as an independent variable was also entered into the logistic regression model. Only the attitude variable was found to make a statistically significant contribution to the model and as a result age was removed from the model. The model explained between 21.6% and 29.1% of the variance in willingness to support sexual matters, and correctly classified 71.9% of cases. Attitudes were found to significantly predict willingness ($p < 0.05$), reporting an odds ratio of 1.17. This indicated that participants who reported more liberal attitudes were more likely to report being 'Reactive and Open' to supporting sexual matters.

iii) Staff's willingness to provide support with sexual matters will be positively associated with their feelings of confidence and comfort regarding this subject (Hypothesis 3)

To meet the assumptions of the Chi-square tests for independence participants' ratings on their feelings of confidence were collapsed into categories of 'Confident' and 'Very Confident'. Similarly participants' ratings on their feelings of comfort were collapsed into categories of 'Comfortable' and 'Very Comfortable'. Chi-square tests found no significant association between willingness and confidence x^2 (1) = 0.14 p = 0.71, and willingness and comfort x^2 (1) = 0.05, p = 0.82.

Post hoc analysis (2)

Spearman's rho correlations and Chi-squares were carried out on the participant variables of total/current time working in services, religion, education, and training to test for relationships between the variables, the attitude scores and willingness categories. Chi-squares were also carried out between participants' ratings of confidence and comfort and attitudes. None of the analyses were significant ($p > 0.05$), although trends were found for the association between attitudes to women and training ($p = 0.07$) and attitudes to women and education ($p = 0.06$). Participants who had gone onto further education (college or university) and/or had received training on supporting service users' sexuality were more likely to hold 'Very Liberal' attitudes as opposed to 'Liberal' attitudes towards sexuality for women with ID.

Discussion

The results for this study indicated that staff held liberal attitudes towards the sexuality of men and women with ID. An association was also found between these attitudes and staff's willingness to provide support to service users regarding sexual matters. The direction of this association was positive; more liberal attitudes were associated with a greater willingness to offer support. Other hypotheses were not upheld. Staff's feelings of confidence and comfort were not associated with their degree of willingness to support sexual matters. Moreover, staff held similar attitudes to men and women regarding risk/vulnerability issues. However, trends were found indicating that staff did hold more liberal views about men compared to women on sexual rights and non-reproductive sexual behaviour.

The findings of this study are consistent with those of recent studies which seem to show a shift to more liberal attitudes towards the sexuality of people with ID (Gilmore and Chambers, 2010). No association was found between gender and risk of sexual exploitation/abuse, indicating that there was no difference in staff's fear about women and men's' vulnerability. One explanation might be that staff are now less concerned about female service users' vulnerability. Nonetheless, the risk issues that staff discussed supporting within their day to day work were all in relation to female service users, implying that staff still have more concerns about the risks to the women that they support. It is possible that the questions exploring risk issues used in this study failed to tap into the concerns that they have. The fact that the study found trends indicating that more liberal views were held towards men compared to women on the subscales of sexual rights and non-reproductive sexual behaviour also supports the contention that less favourable attitudes are held about women expressing their sexuality. McCarthy's (1999) contention that women are

often considered as less sexual then men may be reflected in the staff attitudes reported in this study. However, less than 25% of staff discussed supporting men with sexual matters. It is possible that the differences in attitudes found could relate to the fact that staff simply had greater experience of supporting sexuality issues with women with ID and thus were more aware of the challenges. Moreover, as only trends were found indicating differences in attitudes to men compared to women on these aspects of sexuality, additional research may be warranted to investigate this further.

The results of this study suggest that if staff hold liberal attitudes there is a greater likelihood that they may offer assistance on sexual matters in an open, supportive way. Although an association was found between attitudes and support practices, attitudes alone cannot account for the variance in staff's willingness to offer support. Liberal attitudes were also held by some staff who reported being restrictive with clients they worked with. In line with the Theory of Planned Behaviour (Ajzen, 1991), this suggests that other factors, such as subjective norms or staff's perceived behavioural control, could be impacting on the support that they provide for sexual matters. Surprisingly, staff's feelings of confidence and comfort were not found to be associated with the degree of support they offered. There also did not appear to be a relationship between staff's willingness to provide support and the type of sexual matters they needed to address; helping service users with education issues was most frequently reported by staff who were 'Reactive' and staff who were 'Reactive and Open' in their support practice. Nor were other background factors, like holding religious beliefs or the length of time staff had worked in services, associated with staff's willingness to offer support.

A number of staff reported that they would want to obtain further information for themselves, other staff and/or services users, if asked to support someone with similar sexual matters in the future. Hence, it is possible that a lack of experience, knowledge or understanding of resources to assist with their support practices could impact on staff's degree of willingness to offer support for sexual matters. Nonetheless over half of the staff who participated had already received training about sexuality, and this was not associated with providing open support for sexual matters. Moreover, the majority of staff stated that they would like to receive further training to assist them with supporting service users' sexuality. This suggests that the training that staff had received was inadequate or failed to address the situations they face in practice.

Although this research found that most service users were receiving support for their sexuality, staff were not proactive in providing assistance. Similar results were found by Abbot and Howarth (2007), who reported that staff believed it would be inappropriate or intrusive to proactively offer support. It is possible that staff did not consider raising the topic of supporting sexuality with service users without knowing first that support was needed as a person's sexual life is considered a private matter. This implies that it is the responsibility of the service user to make staff aware when support is required. Nonetheless, staff involved in this study had worked in services for many years, yet most reported that they had few experiences of supporting sexual matters. This indicates that there could be barriers to people with ID accessing support for their sexual needs, for instance knowing that it is okay to talk about sexual matters (Morrison, 2007). Moreover, Pownall (2010) found that people with ID don't have many sources of information on sexual issues and find the information available difficult to access. As a result individuals may be less willing to ask

staff for support, yet need it more. This highlights that more needs to be done to assist people with ID in accessing support for their sexuality.

The results of this study uncovered that people with ID need support from staff on a broad range of sexual matters such as relationship issues, sex education or support with sexual health matters. Most staff reported willingness to help service users with their sexuality, and different types of support approaches were used such as offering advice, or accessing information or resources for service users. Approximately half of the participants were satisfied with the support they provided stating that they would not change anything. Nevertheless, a number of staff reported that they wanted to provide more support for service users in the future. This is encouraging and indicates that staff place an importance on their role supporting service users with their sexual needs.

Strengths and Limitations

One of the key strengths of the study was the use of a mix methods approach to gather data. The ASQ-ID has been used in previous high quality studies (Gilmore and Chambers, 2010) and allowed a thorough exploration of staff's attitudes. Moreover, by using semi-structured interviews data was gathered which has allowed insight to be drawn on the type of sexual matters that staff are asked to support, their support practices and related factors such as training needs. Nevertheless, these strengths need to be considered in light of a number of limitations. If a comparison measure of attitudes to sexuality in the general population was gathered the results may have provided a more robust measure of attitudes. Further research in this area could use the Attitudes to Sexuality Questionnaire - Individuals from the General

Population (Cuskelly & Gilmore, 2007) to do this. Only two staff members reported restrictive support practices. Due to the low frequency count in this category, analysis of the relationship between restrictive support practices and attitudes was not possible. To help ensure the quality of the data gathered, the measures and interviews were conducted face to face with participants. Nevertheless, it is the possible that a social desirability bias may have influenced participants' responses.

Despite these limitations, this exploratory study found interesting results regarding staff's attitudes towards sexuality in men and women with ID. Evidence of a link between staff's attitudes and their willingness to support sexual matters has been found. Important information regarding the nature of supporting service users with sexual matters was also uncovered. Moreover, the results have highlighted that other factors in addition to attitudes may be impacting on the support that people with ID receive for their sexuality, and more work is needed to understand the barriers to this support being delivered.

Research and Clinical Implications

The results for this study provide a useful foundation for further exploration of staff's willingness to support service user's sexuality and associated factors. Though positive attitudes to sexuality were reported, trends were found indicating that staff held less liberal attitudes towards women compared to men on sexual rights and non-reproductive sexual behaviour. As attitudes were found to be associated with support practices, it is possible that this could impact on the quality of support that female service users receive. Supporting sexual matters is not a topic which is easily discussed. It is likely that staff need more

specific training about how to discuss this sensitive issue with service users, thereby giving service users greater confidence to seek the support they desire.

References

Abbott D. & Howarth J. (2007) Still off limits? Staff views on supporting gay, lesbian, and bisexual people with intellectual disabilities to develop sexual and intimate relationships? *Journal of Applied Research in Intellectual Disabilities* **20**, 116 – 126.

Ailey S.H., Marks B.A., Crisp C., Hahn J.E. (2003) Promoting sexuality across the life span for individuals with developmental disabilities. Nursing Clinics of North America **38 (2)**, 229 – 259.

Ajzen I. (1991) The theory of planned behaviour. *Organizational Behavior and Human Decision Processes* **50 (2)**, 179 – 211.

Armitage C.J. & Conner M. (2001) Efficacy of the theory of planned behaviour: a meta-analytic review. *British Journal of Social Psychology* **40 (4)**, 471 – 499.

Brown H. (1994) 'An ordinary sexual life?': A review of the normalisation principle as it applies to the sexual options of people with learning disabilities. *Disability and Society*, **9 (2)**, 123 – 144.

Craft A. & Brown H. (1994) Personal Relationships and Sexuality: the Staff Role. In: *Practice Issues in Sexuality and Learning Disabilities* (ed A. Craft), pp. 1 – 22. Routledge London.

Cuskelly M. & Bryde R. (2004) Attitudes towards the sexuality of adults with an intellectual disability: parents, support staff and a community sample. *Journal of Intellectual and Developmental Disability* **29 (3)**, 255 – 264.

Cuskelly M. & Gilmore L. (2007) Attitudes to sexuality questionnaire (individuals with an intellectual disability): Scale development and community norms. *Journal of Intellectual and Developmental Disability* **32 (2)**, 214 – 221.

Dunn D. (2001) Sexual Health. In *Meeting the Health Needs of People who have a Learning Disability* (eds J. Thompson & S. Pickering), pp 211 – 233. Bailliere Tindall, United Kingdom.

Faul F., Erdfelder E., Lang A.G. & Buchner A. (2007) G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods* **39 (2)**, 175-191.

Garbutt R. (2008) Sex and relationships for people with learning disabilities: a challenge for parents and professionals. *Mental Health and Learning Disabilities Research and Practice* **5**, 266-277.

Gilmore L. & Chambers B. (2010) Intellectual disability and sexuality: attitudes of disability support staff and leisure industry employees. *Journal of Intellectual and Developmental Disability* **35**, 22 – 28.

Grieve A., McLaren S., Lindsay W. & Culling E. (2008) Staff attitudes towards the sexuality of people with learning disabilities: a comparison of different professional groups and residential facilities. *British Journal of Learning Disabilities* **37**, 76 – 84.

Hsieh H.F. & Shannon S.E. (2005) Three Approaches to Qualitative Content Analysis. *Qualitative Health Research* **15 (9)**, 1277 – 1288.

McCarthy M. (1996) The sexual support needs of people with learning disabilities: a profile of those referred for sex education. *Sexuality and Disability* **14 (4)**, 265 – 279.

McCarthy M. (1999) Sexuality and Women with Learning Disabilities. Jessica Kingsley Publishers, London.

McCarthy M. & Thompson D. (1997) A prevalence study of sexual abuse of adults with intellectual disabilities referred for sex education. *Journal of Applied Research in Intellectual Disabilities* **10 (2)**, 105 – 124.

McConkey R. & Ryan D. (2001) Experiences of staff in dealing with client sexuality in services for teenagers and adults with intellectual disability. *Journal of Intellectual Disability Research* **45 (1)**, 83 – 87.

Millard, L. (1994) Between ourselves, experiences of a woman's group on sexuality and sexual abuse. In: *Practice Issues in Sexuality and Learning Disabilities* (ed. A. Craft), (1994), pp. 133 – 152. Routledge, London.

Morrison, C. (2007). *Draft Report: People Should Tell You Stuff*. A report from the TASC Agency on a consultation finding out more about what young people with a learning disability need when it comes to sexual health services. NHS Health Scotland. Available at: http://www.healthscotland.com/uploads/documents/3289-Final%20DRAFT%20Full%20Report%20People%20should%20tell%20you%20stuff.pdf (accessed 20th July 2011).

Murray J.L. & Minnes P.M. (1994) Staff attitudes towards the sexuality of persons with intellectual disability. *Australian and New Zealand Journal of Intellectual Disability* **19 (1)**, 45 – 52.

Nihira K., Leland H. & Lambert N. (1993) Adaptive Behaviour Scale-Residential & Community: Second Edition. Pro-Ed Publishing, Austin, Texas.

Oxford Essential English Dictionary (2011). University Press, Oxford.

Pownall J. (2010) Health knowledge and expected outcomes of risky behaviour: a comparative study of non-disabled adolescents and young people with intellectual and physical disabilities. Unpublished PhD.

Pownall J.D., Jahoda A., Hastings R. & Kerr L. (2011) Sexual understanding and development of young people with intellectual disabilities: mothers' perspectives of within-family context. *American Journal of Intellectual and Developmental Disabilities*, **116 (3)**, 205 – 219.

Pownall J.D., Jahoda, A. & Hastings, R. (In press) Sexuality and sex education of adolescents with intellectual disabilities: mothers' attitudes, experiences, and support needs. Submitted to *Journal of Intellectual and Developmental Disability*.

Rose J. & Holmes S. (1991) Changing staff attitudes to the sexuality of people with mental handicaps: an evaluation comparison of one and three day workshops. *Mental Handicap Research* **4 (1)**, 67 – 79.

Ryan D. & McConkey R. (2000) Staff attitudes to sexuality and people with intellectual disabilities. *The Irish Journal of Psychology* **21 (1-2)**, 88 – 97.

Ward K.M., Trigler J.S. & Pfeiffer K.T (2001) Community services, issues, and service gaps for individuals with developmental disabilities who exhibit inappropriate sexual behaviours. *Mental Retardation* **39 (1)**, 11 – 19.

SPSS 14 Quick Guide (2009) Leeds Metropolitan University, Leeds.

Chapter 3: Advanced Clinical Practice I

Reflective Account

Facilitating reflective practice within a multidisciplinary team trained in psychosocial interventions: roles, responsibilities and resistance

Author: Andrea Gallagher*[1]

Mental Health and Wellbeing, University of Glasgow*

Address for Correspondence[1]

University of Glasgow

Mental Health and Wellbeing

Gartnavel Royal Hospital

1055 Great Western Road

Glasgow

G12 0XH

Tel: 0141 211 3920

Fax: 0141 211 0356

Email: a.gallagher.1@research.gla.ac.uk

Submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology (D. Clin. Psy.)

Abstract

This reflective account describes my experiences of establishing and facilitating reflective practice groups for multidisciplinary team (MDT) members trained in psychosocial interventions. This growth in MDT members' roles to include the utilisation of psychosocial interventions reflects the local and national developments to increase the availability of evidence based psychological therapies. Such developments have assisted in the expansion of clinical psychologists' role to support team members through consultancy, leadership and training. Pedlar et al's (2001) reflective model has been used to guide this reflective account. I have also highlighted the importance of developing the skills of reflection-on-action, leading to the development of reflection-in-action, as described by Schon (1991). Through writing this account I have examined my experiences within this MDT which have assisted my training and development as a clinical psychologist. The impact of facilitating reflection with team members, and reflecting within this account is explored. It is hoped that my experiences facilitating the reflective practice groups in this MDT, along with writing this account, will assist with my future practice.

Chapter 4: Advanced Clinical Practice II

Reflective Account

Developing the role of the clinical psychologist: managing barriers to self progress when working in teams

Author: Andrea Gallagher*[1]

Mental Health and Wellbeing, University of Glasgow*

Address for Correspondence[1]

University of Glasgow

Mental Health and Wellbeing

Gartnavel Royal Hospital

1055 Great Western Road

Glasgow

G12 0XH

Tel: 0141 211 3920

Fax: 0141 211 0356

Email: a.gallagher.1@research.gla.ac.uk

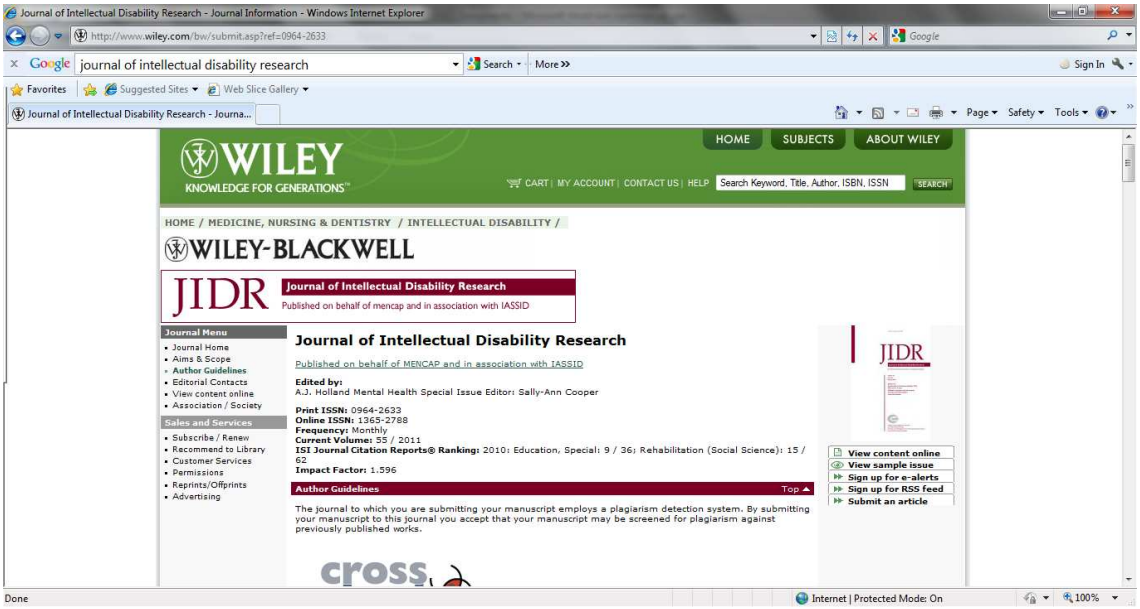
Submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology (D. Clin. Psy.)

Abstract

This reflective account describes my learning experiences of liaising with multidisciplinary team members within a community mental health team on complex cases. Offering consultation to manage the dissemination of psychological knowledge in teams is an important aspect of a clinical psychologist's role. Developing the various aspects of this multi-dimensional role is vital to meet the demands on the profession. Rolfe et al's (2001) reflective model was used to facilitate reflection and structure this account. This account has assisted me with examining the impact that systems have on my growth as a clinical psychologist and the progress that I aspire to make as I develop within my roles.

Appendices

Appendix A: Requirements for submission to Journal of Intellectual Disability Research



Full details can be found at http://www.wiley.com/bw/submit.asp?ref=0964-2633

Appendix B

Participant Background Information Sheet

Section 1

1. Participant Number:
2. Age:
3. First part of postcode:
4. Employer:
5. Religions affiliation:
6. Do you practice your religion? Yes No Sometimes
7. Time working in learning disability support services (in months)
8. Time working in current post (in months):
9. Level of previous qualifications: High School College University Other

Section 2

10. Have you received training on talking to clients or supporting clients with sexual matters? Yes No

11. Have you received information or training on:

	Not Available	Not at all Helpful	Sometimes Helpful	Generally Helpful	Very Helpful	Extremely Helpful
Your organisation's guidelines on sex and relationships	NA	0	1	2	3	4
The legal position regarding sex and relationships for people with LD	NA	0	1	2	3	4
How to talk to people on relationships or sexual matters	NA	0	1	2	3	4
The resources available to assist supporting sex and relationships	NA	0	1	2	3	4

12. Would you be interested in receiving (further) training on discussing or supporting clients with sexual matters? Yes No

If 'Yes' what topics would you like to receive training on?

_____

_____

Appendix C

Semi-Structured Interview

Confidentiality

Your knowledge as an expert, worked in the field for X months/yrs

Not an easy but an important topic

Want you to talk about your experiences of supporting people who can talk about issues with you, people who can communicate their sexual needs.

"The aim of this interview is to explore your experiences of supporting sexuality with people with intellectual disabilities. This could cover a range of experiences, for example concerns about sexual matters, supporting someone to have a relationship, offering education or advice, or situations in which intimacy may occur. Experiences can be both positive and negative. One thing that involves them all is that they are often emotional experiences. I'll be asking you to think about the last situation which triggered strong feelings in you, or brings back strong feelings to you when you think about it. It is not necessary for you to tell me the person's name, can you tell me if this situation was about a male or female service user?

1. Can you tell me what happened?
    a. What the situation was about?
    b. How it came to their attention?
    c. How they responded?
    d. How they felt?

2. Thinking back to what happened, how confident did you feel? (on 1 – 5 scale)

   And how comfortable did you feel? (on 1 – 5 scale)

3. If a similar situation arose what would you do differently?

_____

_____

4. Do you think there are any barriers to service users accessing support on sexual matters?

_____

_____

Staff's support

Here are some sources of support which are often helpful, were they available to you?

	Not Available	Not at all Helpful	Sometimes Helpful	Generally Helpful	Very Helpful	Extremely Helpful
Your colleagues at work	NA	0	1	2	3	4
Your manager/supervisor	NA	0	1	2	3	4
Other professionals who visit my workplace, e.g. social workers, psychologists	NA	0	1	2	3	4
Support staff who work in other organisations	NA	0	1	2	3	4
Organisational policies	NA	0	1	2	3	4
Information on the law regarding sexuality and learning disabilities	NA	0	1	2	3	4
Professional training	NA	0	1	2	3	4
Books, pamphlets or websites	NA	0	1	2	3	4
GP or family planning centre	NA	0	1	2	3	4
Learning disability charities or support groups	NA	0	1	2	3	4
(other source)						

5. Tell me how supporting sexuality fits with the broader remit of your role and other tasks you do as a support worker?

_____

_____

6. What would be the most difficult things to deal with and most straightforward with regards to sexuality?

_____

_____

Appendix D

Attitudes to Sexuality Questionnaire (Men with an Intellectual Disability)

We are interested in your views about sex and relationships for men with intellectual disabilities. For each of the following statements please tell me the option that best represents your opinion.					
	Strongly Disagree	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
1. With the right support, men with an intellectual disability can rear well-adjusted children.					
2. Provided no unwanted children are born and no-one is harmed, consenting adult men with an intellectual disability should have the choice to live in a heterosexual relationship.					
*Men with an intellectual disability are more at risk of sexual abuse or exploitation than men without an intellectual disability (R)					
3. Consenting adult men with an intellectual disability should have the choice to be in a homosexual relationship if they so desire.					
5. Men with an intellectual disability have less interest in sex than other non-disabled men. (R)					
6. If men with an intellectual disability are in a committed relationship, they should be discouraged from having children. (R)					
8. Sterilisation should be used as a means of inhibiting sexual desire in men with an intellectual disability. (R)					
9. Masturbation should be discouraged among men with an intellectual disability. (R)					
*It is necessary for staff to protect men with an intellectual disability from sexual abuse or exploitation (R)					
10. Discussions on sexual intercourse promote promiscuity/sexual activity in men with an intellectual disability. (R)					
11. Men with an intellectual disability should only be permitted to marry if either they or their partner has been sterilised. (R)					
12. Masturbation in private for men with an intellectual disability is an acceptable form of sexual expression.					
13. Men with an intellectual disability typically have fewer sexual interests than other non-disabled men. (R)					
15. Men with an intellectual disability are unable to develop and maintain an emotionally intimate relationship with a partner. (R)					
16. Sex education for men with an intellectual disability has a valuable role in safeguarding them from sexual exploitation.					
17. In general, sexual behaviour represents a major problem area in management and caring for men with an intellectual disability. (R)					
18. Sexual intercourse should be permitted between consenting adults with an intellectual disability.					
19. Group homes or hostels for adults with an intellectual disability should be either all male or all female, not mixed. (R)					
20. Care staff and parents should discourage men with an intellectual disability from having children. (R)					
*Staff need to ensure that sexually active men with intellectual disabilities do not pose a risk to others. (R)					
22. Men with an intellectual disability have the right to marry.					

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
23. It is a good idea to ensure privacy at home for men for an intellectual disability who wish to masturbate.					
25. Sexual intercourse should be discouraged for men with an intellectual disability. (R)					
26. Advice on contraception should be fully available to men with an intellectual disability whose level of development makes sexual activity likely.					
27. Men with an intellectual disability are more easily stimulated sexually than people without an intellectual disability. (R)					
28. Marriage between adults with an intellectual disability does not present society with too many problems.					
29. Sterilisation is a desirable practice for men with intellectual disabilities.(R)					
31. Masturbation should be taught to men with an intellectual disability as an acceptable form of sexual expression in sex education courses.					
32. Marriage should not be encouraged as a future option for men with an intellectual disability. (R)					
33. Men with intellectual disabilities should be permitted to have children within marriage.					
34. Men with an intellectual disability have stronger sexual feelings than other non-disabled men (R)					
*Reducing sexual freedom ensures that the risks of sexual exploitation or abuse to men with an intellectual disability are minimised (R)					

* = added questions regarding risk/vulnerability, R = reverse scoring

Attitudes to Sexuality Questionnaire (Women with an Intellectual Disability)

We are interested in your views about sex and relationships for women with intellectual disabilities. For each of the following statements please tell me the option that best represents your opinion.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. With the right support, women with an intellectual disability can rear well-adjusted children.					
2. Provided no unwanted children are born and no-one is harmed, consenting adult women with an intellectual disability should have the choice to live in a heterosexual relationship.					
*Women with an intellectual disability are more at risk of sexual abuse or exploitation than women without an intellectual disability (R)					
3. Consenting adult women with an intellectual disability should have the choice to be in a homosexual relationship if they so desire.					
5. Women with an intellectual disability have less interest in sex than other non-disabled women. (R)					
6. If women with an intellectual disability are in a committed relationship, they should be discouraged from having children. (R)					
8. Sterilisation should be used as a means of inhibiting sexual desire in women with an intellectual disability. (R)					
9. Masturbation should be discouraged among women with an intellectual disability. (R)					
*It is necessary for staff to protect women with an intellectual disability from sexual abuse or exploitation (R)					
10. Discussions on sexual intercourse promote promiscuity/sexual activity in women with an intellectual disability. (R)					
11. Women with an intellectual disability should only be permitted to marry if either they or their partner has been sterilised. (R)					
12. Masturbation in private for women with an intellectual disability is an acceptable form of sexual expression.					
13. Women with an intellectual disability typically have fewer sexual interests than other non-disabled women. (R)					
15. Women with an intellectual disability are unable to develop and maintain an emotionally intimate relationship with a partner. (R)					
16. Sex education for women with an intellectual disability has a valuable role in safeguarding them from sexual exploitation.					
17. In general, sexual behaviour represents a major problem area in management and caring for women with an intellectual disability. (R)					
18. Sexual intercourse should be permitted between consenting adults with an intellectual disability.					
19. Group homes or hostels for adults with an intellectual disability should be either all male or all female, not mixed. (R)					
20. Care staff and parents should discourage women with an intellectual disability from having children. (R)					
* Staff need to ensure that sexually active women with intellectual disabilities do not pose a risk to others. (R)					
22. Women with an intellectual disability have the right to marry.					

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
23. It is a good idea to ensure privacy at home for women for an intellectual disability who wish to masturbate.					
25. Sexual intercourse should be discouraged for women with an intellectual disability. (R)					
26. Advice on contraception should be fully available to women with an intellectual disability whose level of development makes sexual activity likely.					
27. Women with an intellectual disability are more easily stimulated sexually than people without an intellectual disability. (R)					
28. Marriage between adults with an intellectual disability does not present society with too many problems.					
29. Sterilisation is a desirable practice for women with intellectual disabilities. (R)					
31. Masturbation should be taught to women with an intellectual disability as an acceptable form of sexual expression in sex education courses.					
32. Marriage should not be encouraged as a future option for women with an intellectual disability. (R)					
33. Women with intellectual disabilities should be permitted to have children within marriage.					
34. Women with an intellectual disability have stronger sexual feelings than other non-disabled women (R)					
*Reducing sexual freedom ensures that the risks of sexual exploitation or abuse to women with an intellectual disability are minimised. (R)					

* = added questions regarding risk/vulnerability, R = reverse scoring

Appendix E: Ethical Approval Letter

Ms Andrea Gallagher
Xxxxxx
Xxxxxxx
Xxxxxxx

Dear Ms Gallagher

Medical Faculty Ethics Committee

Project Title: ***Investigating staff's attitudes and willingness to support men and women with mild intellectual disabilities on matters relating to their sexuality***

Project No.: ***FM07909***

The Faculty Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study now that the requested revisions have been incorporated. They are happy therefore to approve the project, subject to the following conditions:

- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- If the study does not start within three years of the date of this letter, the project should be resubmitted.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely

Dr David Shaw

Faculty Ethics Officer

Dr D Shaw
Lecturer in Ethics & Ethics Officer

School of Medicine, University of Glasgow, 378 Sauchiehall Street, Glasgow, G2 3JZ

Tel: 0141 211 9755
E-mail: david.shaw@glasgow.ac.uk

Appendix F: Participant Consent Form

UNIVERSITY
of
GLASGOW

Doctorate in Clinical Psychology

Centre Number:

Participant Identification Number:

CONSENT FORM

Investigating staff's attitudes and experiences of supporting men and women with mild intellectual disabilities on matters relating to their sexuality

Researcher: Andrea Gallagher

Please initial box

1. I confirm that I have read and understand the information sheet dated July 2010 for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being effected. ☐

3. I agree to take part in the above study. ☐

Name of staff	Date	Signature
Name of Person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature

Appendix G: Participant Covering Letter

UNIVERSITY
of
GLASGOW

Doctorate in Clinical Psychology

Hello,

Thank you for taking the time to read the information sheet. My name is Andrea Gallagher and I am currently training to be a clinical psychologist at the University of Glasgow. As part of my training program I am carrying out research about supporting people with learning disabilities around sexual matters. My supervisors are Professor Andrew Jahoda and Dr Jaycee Pownall.

I hope to recruit support staff who work with people with mild learning disabilities in their client's own homes. You have been asked to consider volunteering for this study as you carry out this role. We're interested in exploring staff's attitudes and experiences of supporting people with learning disabilities with sexual matters. We would also like to speak to staff who may not have had the experience of supporting the people they work with around sexual matters.

If you are interested in volunteering for this study you can do so by contacting me either by email or phoning me at the number given at the bottom of this page. Alternatively you can leave your signed consent form in the enclosed stamped addressed envelope with your manager. I will routinely contact your manager to enquire if there are any forms to pick up. In addition, you can post your signed consent form to me in the stamped addressed envelope in the pack. *If you volunteer via consent form please put a contact number or email on the form so that I can get back to you.* It is also important to point out that if you wish to withdraw your consent you can do so at any time, you will not be identifiable from any information collected and all information will be stored in a secure way.

If you are interested in this study but would like to find out more about it or ask any questions before deciding to volunteer then please do not hesitate to phone me or drop me an email.

Thank you for reading the materials and I hope to have the opportunity to speak with you in the future.

Kind regards,

Andrea Gallagher
Trainee Clinical Psychologist

Enclosed: Participant Information Sheet & Participant Consent Form

Telephone: 07831951450 Email: 0807828g@student.gla.ac.uk

Appendix H: Participant Information Sheet

UNIVERSITY
of
GLASGOW
Doctorate in Clinical Psychology

Title of Project: Investigating staff's attitudes and experiences of supporting men and women with mild intellectual disabilities on matters relating to their sexuality

Information form for participants

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.
Thank you for reading this

What is the purpose of the study?

Residential support staff and the organisations within which they work have an important role in the lives of people with learning disabilities. Studies have shown that the opportunities that people with learning disabilities have to develop more intimate relationships and gain information are likely to be influenced by staff's attitudes and behaviour.
With regards to sexual issues, people with learning disabilities are less likely to get support from their peers and research shows that the sex education available to them did not provide them with all the information they needed. Hence people with a learning disability may be more reliant on staff for information and support with sexual matters.

Previous studies have found that how people act is influenced by different things including their attitudes. There has been some research on staff's attitudes, however, not much has been found out on attitudes to sexuality in men with a learning disability compared to women with a learning disability. The purpose of this study is to find out about support staffs attitudes about sexuality in men and women with learning disabilities. Also, as there has been little research on staff's experiences of supporting sexuality with the clients they work with we aim to find out more about this.

It is hoped that this study will lead to a greater understanding of the needs of support staff with supporting sexual matters with their clients. This may help other professionals such as psychologists, understand the types of concerns that staff have, or the ways that staff can be better supported to carry out their role supporting clients.

Why have I been chosen?

You have been asked to participate in this study as you have worked with people with learning disabilities in their homes for a period of time that would have allowed you to build a supportive relationship with them. This supportive relationship would be necessary for you and the clients you work with to feel comfortable to talking about sexual matters.

This study aims to recruit around 40 support staff so that we can understand the various types of support experiences you have had. Due to the predominance of women working in this role, only female support staff have been asked to participate.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form which you will be given a copy of. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not have any further implications.

What do I have to do?

If you decide to take part in this study you will be asked to meet with the main researcher, Andrea Gallagher, for around 45 minutes in your place of work. You will be asked to complete a questionnaire on attitudes to sexuality in men and women with learning disabilities and a questionnaire on background factors, e.g. how long you have worked as a support worker. You will be asked to talk about your experiences of supporting sexual matters with the clients you work with. If you have not supported sexual matters, we can discuss your thoughts around why this may be and how you would anticipate supporting sexual matters. With your agreement we would like to record the interview so that we can talk more freely together.

What are the possible disadvantages and benefits of taking part?

We do not anticipate any disadvantages of taking part in this study.

Though you will receive no direct benefit from taking part in this study, the information that is collected will give us a better understanding of the support needs that staff may have and any gaps in support systems. Also, we may gain an understanding of the need to clarify or develop staff's support role and the protocols within which you can confidently work. Hence if you agree to take part in this study you would be helping to contribute to this knowledge base.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Unless there is evidence that you or the people you care for are at an immediate risk of significant harm, in which case the researcher will try and obtain appropriate help, after discussion with yourself. You will be identified by an ID number and any information about you will have your name and address removed so that you cannot be recognised from it.

What will happen to the results of the research study?

It is hoped that this study will provide useful information on staff's attitudes and experiences of supporting sexual matters with the clients they work with. When this study is completed the main researcher, Andrea Gallagher, will write to you with a summary of the results. This research will form part of the main researcher's Doctorate in Clinical Psychology. It is also anticipated that the results of this research will be published in a related journal. You will not be identified in any report or publication of this study.

Who is organising and funding the research?

Professor Andrew Jahoda and Dr Jaycee Pownall who work at the Department of Psychological Medicine within the University of Glasgow have organised this research with the main researcher. The main researcher, Andrea Gallagher, is a Trainee Clinical Psychologist training on the Doctorate in Clinical Psychology course in the same department. Any funding required for this research will be provided by the Department of Psychological Medicine within the University of Glasgow.

Who has reviewed the study?

This study has been reviewed by the Faculty of Medicine Ethics Committee.

Contact for Further Information

If there is anything else you want to know or anything you want to clarify please do not hesitate to contact the main researcher, Andrea Gallagher, or you can contact my supervisors, Professor Andrew Jahoda or Dr Jaycee Pownall at the following:

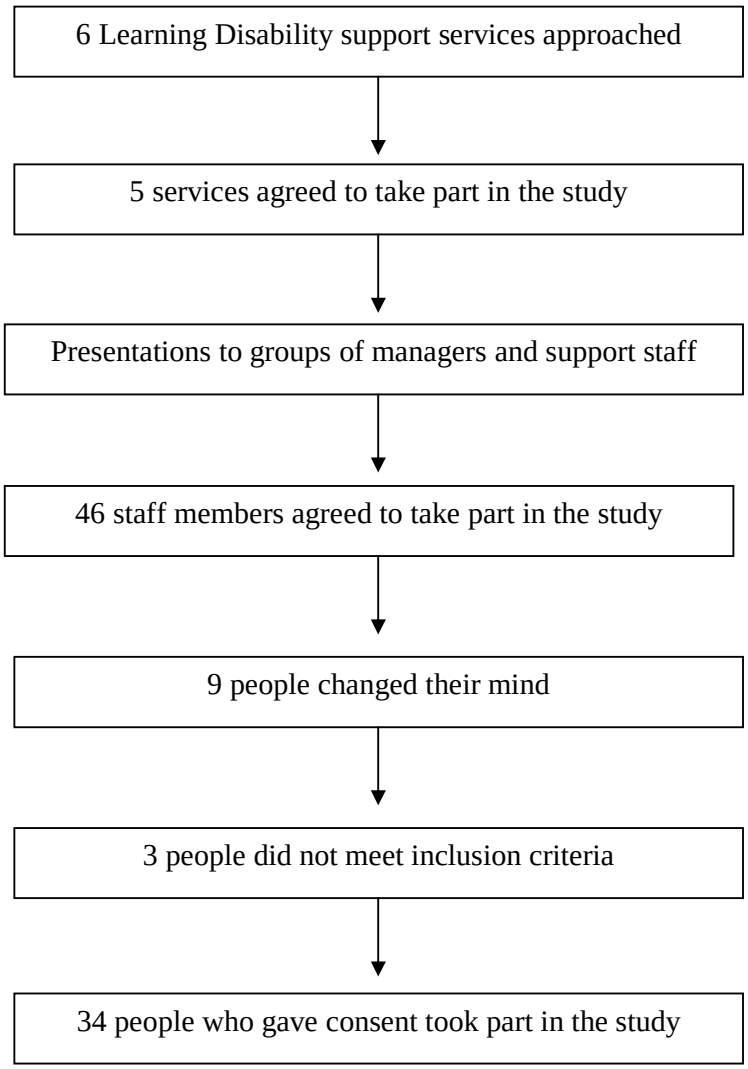
Andrea Gallagher:
Telephone: 07831951450 Email: 0807828g@student.gla.ac.uk

Professor Andrew Jahoda:
Email: Andrew.Jahoda@glasgow.ac.uk

Dr Jaycee Pownall:
Email: Jaycee.Pownall@glasgow.ac.uk

Thank you for your time and for considering this study.

Appendix I: Flow Chart of Recruitment



Appendix J: Examples of quotes from categories developed from content analysis of the semi-structured interviews

Category: Willingness	Definition of the category	Quotes from category
Restrictive	Participants described using support practices which deliberately restricted the sexuality of the service user.	"she was wanting to be sexually active with people but we weren't allowing that because of this order and it was felt that she wasn't able to make the informed choice... I was just sort of following protocol and stuff....it wasn't just sexual relationships it was very much any boyfriend/girlfriend scenario was sort of very closely monitored and we were to be there at all times"
Reactive	Participants responded to the service user's request for assistance with sexual matters/ noted that assistance was required with sexual matters and provided some support.	"she had a letter…she had written the letter and she felt that the guy that she had been in the relationship with had raped her.... within my support time, as part of my role, I would take her to the police station to allow her to speak to the police offers regarding it, which I did do. As far as being involved in it I didn't make any judgement, it's not my place to judge this or doubt this or think what is this about. It's not my role and it's not my place.... (Have you given this person any additional support or spoken about it in any other way at all?) no." "....we do something different every day, on a Wednesday he goes to the gay bars, so whoever is on a Wednesday has got to go to the gay bars with him, that's in his support plan.... the issue that will come out is "I'll never find love, I'll never find love" . He wants you to fix everything for him and you cannie...we're support workers, we're not trained in anything else.... To get him out for a while we'd say "alright, do you want to go to the bars tonight" ..but even at that he didn't..... I'll say to him I've not got the answers for you as I'm not trained in that kind of thing, but if you want to speak to me about something else, I'm here I'll listen to you. But he doesn't listen to you as he wants to hear the answer that he wants to hear, so you just try and get round, change the subject...."
Reactive and open	Participants responded to the service user's request for assistance with sexual matters/noted that assistance was required with sexual matters and provided some support. Participants in this category also attempted to find additional means to support service user's sexuality	"spoke to him a few times about it, about how to meet different kinds of women because obviously he is not going out with this lady, and trying to get him to understand that there are other women…would he like to go to some clubs….that he could maybe meet people at...I waited like a day….then I spoke to him again but I did notify his CPN…we did speak about capacity and his understanding and stuff….would it be sexual education…..I did say to him…you ever want to talk again then just ask..I just reinforced that the now that you can get another girlfriend somewhere else" "we knew there was a relationship there….I started supporting her out to maybe a meal and then she asked if he could say over.... We went along with that and thought okay, we'll do day interaction first, see how they cope without staff being involved in their conversations….leave them to chat themselves and see how they

		get own.....I said do you know what sex is "oh not really" I was like "oh God".....I went away on my own and phoned some of my mates and said right, you talk to young people about sexual education, can I come to you as a resource? I gave him a bit more information; spoke to his partner who did legal stuff as a social worker, so legally where do we stand.... I think because I didn't know how to talk to someone about their sexuality, I'm like, how am I going to speak to this person, so I thought right, well I don't know enough so I'm going to go elsewhere to get information and make sure there are things in place if it was needed."

Category: Sexual matters raised which required support	**Definition of the category**	**Quotes from category**
Education Issues: personal safety/acceptable behaviour in relationships/ boundaries	The service user's lack of knowledge about acceptable behaviour and safety within relationships required support.	"Education carried out about how to be safe and how to keep yourself safe, I think more than the sex side or the sexual side…within a relationship how to be safe, how to spot that somebody….if they have given her things….there might be an ulterior motive to that, I don't know them that well so why are they being so nice to me?" "She didn't realise why Y was falling out with her because she was having a kiss and a cuddle with the other one as well when he wasn't there, or she was up spending too much time dancing with one, so it was getting it was going to end up hand bags at dawn up here, we were having to watch the situation, sit down and explain to X that she had to be careful, it was alright to be friends with everybody but if she was going to have a special friend then that was fine, but she was going to have to keep her kisses and cuddles to one rather than getting caught up in the centre"
Education Issues: sex education	The service users' lack of knowledge on sexual matters required support.	"what she thought having sex was, I had discussions with her, this is the vagina, this is the penis, that's how basic it got so she could understand, and this is what you do….I was like "you'll need to be very clear X, cause you'll need to go to the doctor and get contraception" I said " you'll need to protect yourself as well, you'll need to speak to Y and Z to find out if they have got any other sexual partners to protect yourself.....She would say she is having intercourse with the other guy, so I'd have to speak to her about that what's your understanding of intercourse?" "she said to me "what's a blow job"... I then tried to explain to her the best I could what it was, I then had to go into sexual health and stuff as well, you shouldn't be doing these kinds of things unless you are using contraceptives. Tried to explain to her that she really should be in a loving relationship before she decides she is ready to move forward with sex and stuff"

Education Issues: emotional impact of parenting	The service user appeared to require knowledge on how emotionally challenging parenting could be.	"One service user will comment on having babies....I did speak to her about it….I said " you know its fine saying you want the baby but it's looking after the baby yourself and doing everything when you can't really do an awful lot for yourself so how would you cope with that?" "so it was about us supporting her throughout, it's not just about having a baby it's about what happens after you have a baby, or its very painful giving birth to a baby….it's on the whole counselling and advising and telling her about the emotional issues of giving birth and the pain of giving birth, it's not just all the joy...I say "X, it's not really all that easy, it's quite hard, and its hard carrying a baby, it's painful"....It's always a constant support to remind her of responsibility, and emotions"
Developing Relationships	Support issues raised regarding the service user forming a relationship or their relationship developing.	"He was asking for a pen pal, so we managed to organise this but he took that a wee bit far and sent her a valentines saying that he loved her, but he has never met the girl. After conversations with him I was saying to him, is it actually a pen pal that you want or is it somebody to go out with, he said it's somebody to go out with, so it's not actually a pen pal that he is looking for." "She has physical disability which means that if she is to have potentially sex she would need our support. And she has spoke about that wanting our support with that.... supporting her into bed and supporting her out of bed.....just because physically her body doesn't enable her to do that, we would not be there, that's up to her and her partner, however, she would need our support after it, to get a shower and different things"
Risk issues	Issues regarding service user's vulnerability were raised, or the service user raised allegations of abuse and support was given in relation to such issues.	"very complex individual who had a horrific experience when she was younger, was sexually abused and open to sexual exploitation. At one point it was thought she was being groomed. She used to go out on her own at this point she wasn't under guardianship so she was free to go out, and she would come back 2 or 3 days later, when she came back she would be self harming..she would come up and tell us that she had been with some males and we knew that they had taken advantage of her sexually….groups of guys who didn't have a LD…..This continued over the years and it still is to this day, even although she is under guardianship" "They just started getting close as a couple would but the female I'm supporting only wanted it more like a friendship but the male wanted more. She didn't really know how to deal with this....that he was coming on heavy to her and he was kissing her more and was trying to touch her and she was clearly upset by it and she did say to me that she just really wanted to be friends and I think he was making sexual remarks that she didn't like."

Inappropriate Behaviour	Issues regarding a service user's inappropriate behaviour were identified.	"the guy was verbally suggestive to female staff, I know that some staff felt threatened by it. It was a problem obviously with this person"
Sexual Health Matters	The service user required support on matters relating to sexual health issues.	"she thinks she is now pregnant and her boyfriend thinks she is pregnant too so we obviously had to support her in that area...we got a pregnancy kit and we did that with the service user, myself and another college" "Smear test, the service user being called into have one, we then had the issue well, because she is over a certain age, 27, but as we know it not sexually active but she was saying she was sexually active so I had to phone the GP to ask should we be putting her through this because the girl is in a wheel chair and it is a very difficult and invasive procedure..."

Category: Support offered	**Definition of the category**	**Quotes from category**
Accessed information or resources for service users	Staff supported service users by providing them with information or resources/services which assisted in their support with sexual matters.	"we managed to access this (sex education pack) I got from a link nurse" "took her to the (sexual health) clinic to check and see if she was okay and see if she had caught any disease"
Supported the service user to develop relationships	Staff offered physical support to the service user, or helped them to socialise, to assist them with developing their relationships.	"suggested to the female if she would like to go out for a meal with this male during the week and given that she can't go out on her own we even suggested that the staff go into the restaurant and sit at the other end and let them two have some time on their own to have a meal." "we did go to clubs and parties and stuff"
Spoke to relevant others	Staff spoke to staff, family members or other professionals to clarify the situation, and/or contacted relevant professionals to access further support or information.	"I spoke to his key worker and said "we'll need to start talking about safe sexual practices"... I'm working with the gentleman's key worker going through the pack (sex education pack)." "I have spoken to the disability link nurse and she is going to get some DVDs with sexual awareness and I have spoken to the service user, we can provide you with this information"

Talked to the service user	Staff spoke to the service user about the sexual matters raised, attempted to clarify the support need, offered advice/information/options.	"just talking to the person...offer a different way to this person.... I was trying to explain, sometimes people might be upset if you do that, and I wouldn't speak like that if you are trying to get someone's attention.....I said what I would do is say how are you and try and open up, how you would" "I told her a few times 'if X is really annoying you just come and tell me and I'll speak to him …..I used to say 'Y just tell him to go away and give you a bit of space if you want to dance with the girls or whatever else"

Category: What the participant would do differently	**Definition of the category**	**Quotes from category**
Would not do anything differently	Staff stated that they would not change the support that they offered.	"No I think I dealt with that situation they way I should have" "I think probably I wouldn't probably have changed anything"
Obtain information/support for self and/or other staff	Staff explained that they would gain further information for themselves and/or other staff that would inform their practice.	"Definitely bring a lot more outside input I think, and tap into different things that are there…getting talks for staff and making everything really out in the open….So staff are confident cause I think if staff were confident and comfortable then they'd be able to deal with situations as they came up, not even reacting to situations but just talking about things in general as well so it is really comfortable, really natural and wouldn't become this issue" "I'm not saying training, but someone speaking to me about someone with these issues and how to deal with them. Only if someone offered training"
Obtain information/support for service user	Staff stated that they would gather more information for the service user or support the service user to access information or services.	"I think it would be a good idea for him to learn about relationships. We were going to get more information for him to sit at some sort of presentation. We were going to get all the guys to go as it would be beneficial to all of them. I don't know what happened with that." "I would try and ensure they were more informed as they might find themselves in a situation they wouldn't want to be in."

Appendix K: Major Research Project Proposal and Addendum

Major Research Project Proposal

Investigating staff's attitudes and willingness to support men and women with mild intellectual disabilities on matters relating to their sexuality

Abstract

Background & Aims: Emotional and psychological wellbeing is influenced by many factors, including a person's ability to understand and express their sexuality. People with intellectual disabilities rely on staff/carers to support them with sexual matters. Attitudes can influence behaviours, and staff's attitudes to sexuality in people with intellectual disabilities have been found to be generally liberal. However particular concern regarding women's vulnerability to sexual exploitation may influence attitudes towards women compared to men, and how staff provide support. Despite findings regarding attitudes, there is a dearth of research investigating staff's experience of supporting sexual matters. The aim of this exploratory study is to investigate residential staff's attitudes towards the sexuality of men and women with an intellectual disability. Staff's willingness to provide support and their experience of supporting the sexual needs of clients will also be explored.

Methods: Forty female residential support workers will complete a socio-demographic questionnaire, Attitudes to Sexuality Questionnaire (Individuals with Intellectual Disability) and a semi-structured interview exploring their experience of supporting sexual matters. Paired t-tests may be used to test for differences in attitudes towards men compared to women with an intellectual disability. A chi-square test may assess whether attitudes to sexuality is associated with willingness to support sexual matters, and if willingness to support sexual matters is associated with feelings of confidence and comfort. Content analysis will be used to explore staff's experiences of providing support and the support systems available for staff.

Applications: This study may highlight staff's support needs, or clarify ways in which staff could develop their role so that they can confidentially work to support client's sexuality.

Introduction

Sexuality is a general term which can be used to describe how people identify and express themselves through intimate relationships and sex/sexual practice (Dunn, 2001), and is critical to emotional and psychological wellbeing (Ailey et al., 2003). However sexuality has been a contentious issue for people with intellectual disabilities. Historically they tended to be viewed through sexual stereotypes, possibly still prevalent, as either asexual, 'the eternal child' or being uncontrollable (McCarthy, 1999). Given that this population of people rely on others for support it is important to gain an up to date understanding of carer's attitudes, and reactions, towards sexuality in people with intellectual disabilities.

Residential support staff and the organisations within which they work have a crucial role in the lives of people with intellectual disabilities. The opportunities that people with intellectual disabilities have to develop more intimate relationships and obtain information are likely to be influenced by staff's attitudes and behaviour (Craft & Brown, 1994). Pownall (2010) found that young people with intellectual disabilities were less likely to discuss sexual issues with their peers and the sex education available to them did not provide adequate information. Hence this population may be more reliant on other sources of information and assistance than their non-disabled peers, which indicates the important role that carers have. In a similar vein, McCarthy (1999) found that the quality of women with intellectual disabilities' sexual experiences was determined by a number of factors, including the availability of sex education and support. Without support and accurate information on sexuality, an already vulnerable population of people are at an increased risk of exploitation and abuse.

Recent research has explored support staff's attitudes towards sexuality, and found that liberal attitudes are associated with staff of a younger age with professional qualifications (Murray & Minnes, 1994) who work within small community based settings (Grieve et al., 2008). However more recent studies have found that age does not significantly impact on attitudes (Gilmore & Chambers, 2010). This recent research which has found that age is not a significant variable could reflect society's continual shift towards more liberal attitudes. Client's vulnerability and gender may also influence staff's attitudes towards their sexuality (Grieve et al, 2008). Gilmore & Chambers (2010) measured support staff's and leisure staff's attitudes using Cuskelly & Gilmore's (2007) modified version of the Attitudes to Sexuality Questionnaire - Individuals with an Intellectual Disability (ASQ-ID; Cuskelly & Bryde, 2004). Gilmore & Chambers (2010) findings, similar to those found in Cuskelly & Gilmore's (2007) community sample, generally found liberal attitudes. However men with intellectual disabilities were believed to have less self control with their sexual feelings than women. Hence it is possible that within mixed gender settings staff could be more protective or restrictive towards women they support to reduce the likelihood of risk situations arising. Gilmore & Chambers (2010) also found that attitudes were less accepting towards sexual freedom for women with intellectual disabilities compared to typically developing women. This could imply that information such as sex education may not be readily available or that sexual expression may not be positively supported. As previously discussed if women do not have the necessary support or knowledge needed to assist them to make informed decisions their vulnerability to exploitation/abuse could be heightened.

It is possible that attitudes to sexual freedom for women with intellectual disabilities may also reflect concerns in relation to their vulnerability to exploitation/abuse. In general, women are more vulnerable than men to exploitation/abuse (McCarthy, 1999). Additionally, intellectual

capacity and communication difficulties can lead to further complications such as informed consent (Craft & Brown, 1994), further increasing vulnerability for women with intellectual disabilities. Millard (1994) reported that the incidence of sexual abuse towards this population of women is high. For example, 61% of women with intellectual disabilities referred to a sex education support service reported that they had been sexually abused (McCarthy & Thompson, 1997). Consequently support staff have a role in protecting the clients that they work with from abuse. Moreover, McCarthy (1996) reviewed the clients referred to this sex education support service and found that the most common reason for women's referrals was due to staff's concerns that the women they supported were sexually vulnerable. Significantly fewer men were referred due to concerns about their vulnerability. Instead, men were more often referred due to their sexual abusive behaviour which was frequently towards other women with intellectual disabilities. Studies have found that perpetrators of sexual abuse are predominantly male (Brown et al., 1995) and generally fall into one of four groups: other people with an intellectual disability, family members, staff/volunteers and other trusted people within the community (McCarthy, 1999; Murphy, 2007). Increasingly it has been found that perpetrators of sexual abuse against women with an intellectual disability are men with an intellectual disability (Brown et al., 1995; McCarthy & Thompson, 1997). Moreover a further risk factor identified was that women with intellectual disabilities were engaged in a sexual relationship with more able men, resulting in a power imbalance with men having more control, increasing women's vulnerability to abuse (McCarthy, 1996; Millard, 1994). Due to such risk factors staff may err on the side of caution and take a protective role within their support. Organisations may have policies guiding staff on how to support people with intellectual disabilities with their sexual needs. However, staff can be unsure about policy content and implementing such policies when sexual matters arise (Grieve et al., 2008).

If staff do not have clear guidance on their role in supporting client's sexual needs, it might be reasonable to suppose that their support practice could be guided by the attitudes that they bring to work. However the theory of planned behaviour (TPB); (Ajzen, 1991) suggests that attitudes alone do not directly predict behaviour. Instead it is a person's perceived behavioural control, their perception of the ease or difficulty of carrying out a behaviour, which affects the formation of behavioural intentions, impacting on behaviour itself. McConkey & Ryan (2001) compared staff working within different environments and found that those working within residential settings were more confident in dealing with incidents of a sexual nature than staff within day settings. Consistent with the theory of planned behaviour staff's confidence appeared to have a significant impact on their practice. Thus, even if staff have liberal attitudes to sexuality, if in practice they lack confidence about dealing with sexual matters then they may be more reluctant to provide support. It is vital to not assume that attitudes towards sexuality in people with intellectual disabilities reflect how support is delivered. Instead it is important to investigate both staff's attitudes and their willingness to provide support.

Despite important findings concerning staff's attitudes to sexuality in people with intellectual disabilities there are a number of gaps within the existing research. Gilmore & Chamber's (2010) study found some differences in attitudes towards men and women; however the ASQ-ID which they used had only one question which investigated attitudes relating to risk issues. It is possible that further questions exploring issues of risk/vulnerability may uncover differences in staff attitudes to men compared to women with intellectual disabilities. Previous studies exploring attitudes have relied on questionnaires (Evans et al., 2009; Murray & Minnes, 1994; Grieve et al., 2008). Although questionnaires can be useful tools that provide reliable and valid data, the respondents are generally constrained in what they can

say by closed questions. Hence, this proposed study will adopt a mixed methods approach using questionnaires to determine staff member's attitudes before going onto use semi-structured interviews to explore staff's experiences of supporting the clients they work with on sexual matters.

Aims & Hypotheses

Quantitative Aims

This research aims to investigate residential staff's attitudes towards the sexuality of men and women with an intellectual disability. Staff's willingness to provide support on sexual matters will also be explored.

Qualitative Aims

To explore staff's experiences of providing support to service users on sexual matters and the support systems available to assist staff with this role.

Hypotheses

1. Staff will hold less liberal attitudes towards the sexual needs of women compared to men.
2. More liberal staff attitudes will be associated with a greater willingness to support their clients' sexual needs.
3. Staff's willingness to provide support with sexual matters will be positively associated with their feelings of confidence and comfort regarding this subject.

Plan of Investigation

Design

This is an exploratory study using a mixed methods design. It will involve a within groups comparison of attitudes to men and women with intellectual disabilities (hypothesis 1). Moreover this study will examine whether there are associations between staff's attitudes to sexuality and their willingness to support sexual matters (hypothesis 2). An examination of willingness to support sexual matters and feelings of confidence and comfort (hypothesis 3) will also be conducted. Finally a content analysis will be carried out to explore staff's experiences of providing support for service users' sexual needs.

Participants

Participants will be female staff working within residential settings supporting people with mild intellectual disabilities. Half of the participants will be those supporting men, and half will be those supporting women, with intellectual disabilities.

Inclusion Criteria

Cuskelly & Gilmore (2007) found that respondent's gender does not significantly influence attitudes towards sexuality in people with an intellectual disability. However, McCarthy (1999) discusses the long standing double standard towards sexuality in females which has predominantly been enforced by men. Hence to control for such possible extraneous variables, and given the predominance of female support staff within intellectual disability services, only women will be asked to participate in this study. Participants will be staff who

are fluent English speakers working within a residential setting. They will be required to meet the minimum of having six months work experience and 8hrs per week supportive contact with a service user. This will ensure that participant's have had time to build a trusting relationship with service users and make it likely that they would feel able to talk about sensitive issues such as sexual matters with them. Participants recruited to the study will be staff supporting clients who have sufficient communication abilities to be able to express their views and comprehend what staff say to them. This will be determined using items from the Adaptive Behavour Scale (ABS – RC: 2); (Nihira et al, 1993) asking whether at least one of the service users they work with can, or have the ability to:

- Talk to others about sports, family, group activities, etc
- Sometimes use complex sentences containing 'because', 'but', etc
- Answer simple questions such as 'what is your name?' or 'what are you doing?'

Exclusion Criteria

Staff working in residential settings where there have been recent incidents, or accusations, of sexual abuse will not be included in this study.

Recruitment Procedures

Participants will be recruited from services that provide residential support for people with mild intellectual disabilities within the Greater Glasgow & Clyde health board area. This area includes five community health and care partnerships (CHCPs) within which potential service providers include, among others, Enable Scotland and Key Housing Association.

Managers within these services will be contacted by the researcher and provided with a rationale and information on the study. The researcher will seek permission from managers to present information about the study at group staff meetings and training events. With permission, the researcher will present information on the proposed research and rationale, and will issue information leaflets and consent forms to groups of staff. Volunteers for the study will either be able to contact the researcher directly, post their consent form to the researcher or leave their consent form within a confidential folder in their manager's office. Volunteers will be asked to indicate on their consent forms whether they support men or women with intellectual disabilities. This will ensure that from the participants recruited an exploration of the experiences of supporting both men and women with intellectual disabilities on matters relating to their sexuality can occur. The researcher will routinely co-ordinate with managers to be informed of potential participants. Additionally, a person independent of this study will carry out follow up phone calls two weeks after dissemination of the information packs to make enquiries regarding potential participants. This is someone with a research background and knowledge of the relevant ethical issues, e.g. informed consent.

Measures & Semi-Structured Interview

The following questionnaires and semi-structured interview will be carried out with each participant in the order described.

Background & Socio-demographic Information (Appendix B)

Section 1:

Socio-demographic information will be obtained on: 1) the participant's date of birth, 2) postcode, 3) religious affiliation, 4) whether religion is practiced, 5) length of time working in intellectual disability services, 6) length of time working in their current employment.

Semi-Structured Interview Exploring Staff's Willingness to Support Service Users' Sexual Needs (Appendix C)

A semi-structured interview will be used to gather information on staff's willingness to provide service users with support on sexual matters and to assist them in describing the nature of their experiences of providing support.

Initially a pilot phase will be used to ensure that the interview procedure and coding system is reliable and to ensure the feasibility of carrying out the interviews and subsequent transcription within the timescale limits. Piloting will determine the duration of the interviews, however it is expected that interviews will last for no longer than 30/40 minutes. Changes will be made if necessary.

Experiences of supporting sexual matters with men with intellectual disabilities will be explored with half of the participants, with the experiences of supporting women explored with the other half of participants. The semi-structured interview will be carried out as follows: firstly the staff will be asked to describe the nature of their role as a support worker.

Then, they will be asked to think about their last experience of providing support on sexual matters. Staff will be asked to give an account of what happened by describing the following: a) the sexual matter that required support, b) how they responded, and why, c) their emotional reaction at that time and if their emotions impacted on their response, d) their comfort and confidence in providing support, and finally their overall reflection of providing support. The interview proposes to cover these topics while maintaining a dialogue on the overall support experience. If participants do not have an experience of providing support on sexual matters, the reasons for this will be explored. Throughout this process service users' confidentiality will be maintained and leading questions will not be used. In addition any prompts required during the interview will be recorded.

It is hoped that participant's willingness to support sexual matters can be coded on a 4 – point scale ranging from 'Restrictive' - 'Proactive'. Interviews are not anticipated to be transcribed verbatim. Instead sections of information associated with the willingness categories will be transcribed. Further content analysis will be carried out on staff's experiences of providing support on sexual matters. Five – point likert scales will be used to code levels or comfort and confidence and staff's overall experience of providing support.

Attitudes to Sexuality Questionnaire (Appendix D)

The Attitudes to Sexuality Questionnaire - Individuals with an Intellectual Disability (ASQ-ID; Cuskelly & Bryde, 2004) has high test-retest reliability ($r = 0.91$) and good internal consistency (Cronbach's alpha > 0.90). Cuskelly & Gilmore (2007) modified this questionnaire, dividing it into two sections to measure attitudes towards sexuality in men

separately from attitudes towards sexuality in women. A factor analysis was carried out on the original 34 item ASQ-ID revealing four meaningful subscales on Sexual Rights, Parenting, Non-Reproductive Sexual Behaviour and Self-Control, reducing the number of questions to 28. Questions are answered on a likert scale ranging from strongly disagree – strongly agree. As the ASQ-ID had only one question on risk/vulnerability issues, a further 4 questions exploring such issues have been added by the current researcher.

This version of the ASQ-ID will be piloted and internal consistency and reliability will be assessed; changes will be made if required.

Background & Socio-demographic Information (continued) (Appendix B)

Section 2:

Information will be collected on participant's awareness of organisational policies and the legal position on supporting people with intellectual disabilities with their sexuality.

Research Procedure

A pilot phase will initially be carried out with two to four individuals completing the measures and semi-structured interview. This is to ensure that the questionnaire and interview are not only reliable, but can engage participants, are comprehendible, not too emotionally difficult to complete and can be carried out in a timely fashion.

The researcher will contact volunteers who have opted into the study and after ensuring that they meet the inclusion/exclusion criteria will arrange a suitable time to meet with them in their place of work. The researcher will arrange with service managers to book a private interview room. Upon meeting the researcher participants will be briefed on the purpose and process of the study and asked to sign a consent form if they have not already done so. Participants will then complete both sections of the ASQ-ID, the background and socio-demographic questionnaire and semi-structured interview within one session in the order stated. Answers will be recorded on the measures or using recording equipment and transcribed. All answers will be anonymised. Time will be allocated at the end of the interview to debrief the participants and answer any questions.

Justification of Sample Size

The primary quantitative analysis will test for a difference in staff's attitudes to sexuality towards men compared to women with intellectual disabilities using a modified version of the ASQ-ID (Cuskelly & Gilmore, 2007). Gilmore & Chambers (2010) used this measure to test whether support staff had different attitudes towards men compared to women with intellectual disabilities. They found a significant difference in attitudes towards men and women's self control in relation to their sexuality, with a small/medium effect size (0.3). However it is anticipated that this study will find a more medium effect size: this study has included questions exploring attitudes towards vulnerability/risk issues. The evidence base has found that women with intellectual disabilities are perceived by support staff as more at risk to sexual exploitation/abuse than men with an intellectual disability (e.g. McCarthy,1996). Consequently it could be argued that a medium effect size will be found between the two groups if this factor is explored. Also, the length of time that participants

had worked with people with intellectual disabilities was not recorded in the Gilmore & Chambers' (2010) paper. This study's participants will have worked with people with intellectual disabilities for at least 6 months thus their attitudes are more likely to be based on more experiences and issues of supporting this client group. Hence a medium effect size is anticipated. Based on an effect size of 0.5, with an alpha level of 0.05 and a power of 0.8 (two tailed) the required sample size is 34 (G*Power 3, Faul et al, 2007). Based on this power calculation this study aims to recruit a minimum of 40 participants, half of the participants will support men with intellectual disabilities and half will support women with intellectual disabilities.

Settings and Equipment

A copy of each of the measures will be used with each participant. Recording equipment will be used to record the semi-structured interviews. The interview and measures will be completed in a private room in participant's place of work.

Data Analysis

Quantitative Analysis

The Statistical Package for Social Sciences (SPSS) will be used to analyse quantitative data. Demographic information about the participants will be presented using descriptive statistics. Data will be tested for normality. If the data meets parametric assumptions paired t-tests will be used to test for gender based differences in staff's attitudes on the ASQ-ID (hypothesis 1). It is anticipated that categorical data will be collected on staff's willingness to provide support, hence a chi-square test will be used to measure the relationship between staff's

attitudes and willingness (hypothesis 2). The relationship between willingness and attitudes will be compared based on gender, e.g. if a participant has completed an interview based on supporting a woman, willingness to support a woman will be compared with their attitudes to women. Additionally a chi-square test will be used test for a relationship between staff's willingness to provide support to clients on sexual matters and their feelings of confidence and comfort (hypothesis 3).

Inter-rater reliability will be used to ensure that the coding and scoring of the interviews are accurate.

Qualitative Analysis

Content analysis (Smith 2004) will be used on data gathered from the semi-structured interview to obtain a description of the type of sexual matters dealt with by staff, their experiences of providing support for such matters and the support systems available for staff.

Health and Safety Issues

Researcher Safety Issues

The researcher will ensure that the interview and questionnaire completion will occur during work hours and in a work setting that is staffed. Consequently if any needs arise others are available to contact. No domiciliary visits will be carried out.

Participant Safety Issues

As stated above, the meetings will occur in a safe environment. Confidentiality and the rationale for the study will principally be explained and participants will have the opportunity to ask any questions. It is not anticipated that a participant will become distressed. Nevertheless the researcher will ensure that a member of staff is available for a participant to talk to if they become distressed with regards to service related issues. If a participant becomes distressed in relation to personal issues, the researcher will assist them in seeking support from their GP. If a participant makes a disclosure suggesting that there is vulnerability or risk to a service users' or another's wellbeing the researcher will act appropriately within the boundaries of confidentiality.

Ethical Issues

University ethical approval will be sought from the University of Glasgow's Faculty of Medicine Ethics Committee. The rationale, purpose and procedure of the study will be explained to participants through an information leaflet and by the researcher before they take part to ensure that they can make informed consent. Participants will also be informed that they can withdraw for the study at any stage. Confidentiality and anonymity will be ensured by coding each participant's questionnaire and interview transcript with participant identifiers removed from the research report. Data will be stored in a locked drawer to ensure confidentiality.

Financial Issues

Stationary costs for paper, envelopes and freepost = £41.90

Timetable

August 2010: Ethics application submitted

September/October 2010: Ethics approval obtained

October 2010 – March 2011: Commence data collection and ongoing analysis

April - May 2011: Complete 1st draft

May 2011: Draft submitted to supervisor

May – July 2011: Revise draft changes

July 2011: Submit research to University

Practical Applications

Residential support staff have an important role in supporting sexuality with the men and women they work with. Consequently any barriers or facilitators related to clients receiving adequate support are important to explore. It is anticipated that areas in which staff themselves require support to enable them to carry out their role may be identified. For example this study may highlight a gap in support systems that staff can access. Additionally the need to clarify or develop staff's support role and the protocols within which they can confidential work may be identified. If staff have training, guidance and support to carry out their role, people with intellectual disabilities should be able to receive necessary support and information on sexual matters. This is vital to help reduce their vulnerability to exploitation/abuse, support their rights and enhance their quality of life.

References

Ailey S.H., Marks B.A., Crisp C., Hahn J.E. (2003) Promoting sexuality across the life span for individuals with developmental disabilities. Nursing Clinics of North America **38 (2)**, 229 – 259.

Ajzen I. (1991) The theory of planned behaviour. *Organizational Behavior and Human Decision Processes* **50 (2)**, 179 – 211.

Brown H., Stein J. & Turk V. (1995) The sexual abuse of adults with learning disabilities: a second incidence study. *Mental Health Research,* **8**, 3 – 24.

Craft A. & Brown H. (1994) Personal Relationships and Sexuality: the Staff Role. In: *Practice Issues in Sexuality and Learning Disabilities* (ed A. Craft), pp. 1 – 22. Routledge London.

Cuskelly M. & Bryde R. (2004) Attitudes towards the sexuality of adults with an intellectual disability: parents, support staff and a community sample. *Journal of Intellectual and Developmental Disability* **29 (3)**, 255 – 264.

Cuskelly M. & Gilmore L. (2007) Attitudes to sexuality questionnaire (individuals with an intellectual disability): Scale development and community norms. *Journal of Intellectual and Developmental Disability* **32 (2)**, 214 – 221.

Dunn D. (2001) Sexual Health. In *Meeting the Health Needs of People who have a Learning Disability* (eds J. Thompson & S. Pickering), pp 211 – 233. Bailliere Tindall, United Kingdom.

Evans D.S., McGuire B.E., Healy E., Carley S.N. (2009) Sexuality and personal relationships for people with an intellectual disability. Part II: staff and family carer perspectives. *Journal of Intellectual Disability Research,* **53 (11)**, 913 – 921.

Faul F., Erdfelder E., Lang A.G. & Buchner A. (2007) G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods* **39 (2)**, 175-191.

Gilmore L. & Chambers B. (2010) Intellectual disability and sexuality: attitudes of disability support staff and leisure industry employees. *Journal of Intellectual and Developmental Disability* **35**, 22 – 28.

Grieve A., McLaren S., Lindsay W. & Culling E. (2008) Staff attitudes towards the sexuality of people with learning disabilities: a comparison of different professional groups and residential facilities. *British Journal of Learning Disabilities* **37**, 76 – 84.

McCarthy M. (1996) The sexual support needs of people with learning disabilities: a profile of those referred for sex education. *Sexuality and Disability* **14 (4)**, 265 – 279.

McCarthy M. (1999) Sexuality and Women with Learning Disabilities. Jessica Kingsley Publishers, London.

McCarthy M. & Thompson D. (1997) A prevalence study of sexual abuse of adults with intellectual disabilities referred for sex education. *Journal of Applied Research in Intellectual Disabilities* **10 (2)**, 105 – 124.

McConkey R. & Ryan D. (2001) Experiences of staff in dealing with client sexuality in services for teenagers and adults with intellectual disability. *Journal of Intellectual Disability Research* **45 (1)**, 83 – 87.

Millard, L. (1994) Between ourselves, experiences of a woman's group on sexuality and sexual abuse. In: *Practice Issues in Sexuality and Learning Disabilities* (ed. A. Craft), (1994), pp. 133 – 152. Routledge, London.

Murphy G. (2007) Intellectual disability, sexual abuse and sexual offending. In: *The Handbook of Intellectual Disability and Clinical Psychology Practice* (eds. A. Carr, G. O'Reilly, P.N. Walsh, & J. McEvoy), pp. 835 – 838. Routledge, London.

Murray J.L. & Minnes P.M. (1994) Staff attitudes towards the sexuality of persons with intellectual disability. *Australian and New Zealand Journal of Intellectual Disability* **19 (1)**, 45 – 52.

Nihira K., Leland H. & Lambert N. (1993) Adaptive Behaviour Scale-Residential & Community: Second Edition. Pro-Ed Publishing, Austin, Texas.

Pownall J. (2010) Health knowledge and expected outcomes of risky behaviour: a comparative study of non-disabled adolescents and young people with intellectual and physical disabilities. Unpublished PhD.

Addendum

It was initially proposed that the participant background information sheet would be completed in two stages; first, demographic information on the participants would be gathered, and second, information on their training and awareness of organisational policies recorded. However, it was decided that it was more appropriate to collect all of the background information together, before moving onto the interview and questionnaire.

The piloting phase indicated that minor changes were required. As all participants involved in the pilot, and most subsequent participants, had only one support experience of assisting sexual matters, the researcher could not specify the gender of the service user which the participants discussed supporting. Initially it was thought some participants may not have experiences of supporting sexual matters to discuss. Hence, questions were devised for such participants on broader issues. Nevertheless, as all participants involved in the pilot had recently supported sexual matters, it was decided that only staff that had support experiences to discuss would be invited to take part in the study. A question exploring staff's views on supporting challenging sexual matters and a question on the support available for staff were removed, as information on these topics was gathered from other questions. The measures were piloted on six participants instead of 2 – 4 participants as originally stated.