Bachelor in Science (Nursing) (BSc (Cur))

RESEARCH PROPOSAL

AN INDEPTH EXPLORATION INTO THE SEXUAL EXPERIENCES OF PEOPLE WITH A MILD OR MODERATE INTELLECTUAL DISABILITY.

Research Proposal submitted to University of Dublin Trinity College, in partial fulfilment of the requirements for the Bachelor in Science (Nursing) (B.Sc. (Cur.))

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DECLARATION OF WORK

I hereby declare that this proposal is entirely my own work and appropriate credit has been given to the references of the work of others.
ABSTRACT
ABSTRACT

BACKGROUND
Historically western society has perceived people with an Intellectual Disability (ID) as sexually deviant or asexual. Although a philosophical shift has emerged in this area, with negative attitudes less pervasive today, people with an ID still remain sexually impoverished and experience a disenfranchised sexual identity. Research inquiry in to this area has focused on the attitudes of staff, parents, the community and people with an ID themselves. Research reveals that obstacles to sexual expression may come in the form of negative attitudinal barriers from others which may lead to the development of a self-fulfilling prophecy, with people with an ID retreating from enjoying sexual experiences and intimacy. The way in which attitudes are shown also greatly influences the type and quality of sexual knowledge that people receive.

RATIONALE FOR STUDY
A detailed literature review revealed that the majority of studies focus on attitudes conveyed by staff or parents with little emphasis offered to the personal narrative of the sexual experiences of people with an ID.

AIM
To seek an in depth understanding of the sexual experiences of people with a mild or moderate ID.

METHODOLOGY
A descriptive phenomenological design was used, using semi-structured interviews to elicit descriptive accounts of sexual experiences. A purposive sample of six people was used. Data analysis was obtained using Colaizzi (1978) framework for phenomenological data. Ethical approval was sought from the Ethics Committee of the affiliated Hospital.

PROPOSED OUTCOMES
It is hoped that a detailed description and extraction of the ‘essences’ of sexual experiences of people with a mild or moderate ID will inform better nursing practice and policy in relation to supporting the sexual needs and health of people with an ID.

RECOMMENDATIONS
That people with an ID be offered more tailored sexual education programmes that enhances their knowledge base and leads to a healthy sexual trajectory. Formal and informal carers should be afforded the same opportunity so that they can enable the sexual expression of people with an ID.

KEY WORDS
Intellectual disability, sexuality, phenomenology, bracketing,
CHAPTER ONE

INTRODUCTION AND IDENTIFICATION OF THE RESEARCH TOPIC

Sexuality is an important part of an individual’s identity, health, lifestyle, orientation and how the person’s body works (Drury et al. 2000). Hinsburger & Tough (2002) assert that is not controversial as to whether people are sexual beings, however the juxtaposition between intellectual disability (ID) and sexuality that has created beliefs that those with an ID are sexless, eternal children or overly promiscuous (McCabe 1999, Oliver et al. 2002). These conflicting opinions have served in formulating panoply of mistakes which spawned a eugenics movement (Ailey et al. 2001). Some acts towards persons with ID included sexual subjugation and involuntary sterilization (Christian et al. 2001).

The principles of normalization and social role valorisation which have gradually being suffused into western society has meant that the right’s based position for people with an ID has changed in terms of access to employment, education and socialisation (Di Giulio 2003). Yet the right for a person with an ID to maximise their sexual potential in terms of their sexual health, entering a relationship, having sexual intercourse or procreating is still not realised (Evan et al. 2009). Hinburger & Tough (2002) find that people with an ID rarely have access to accurate sexuality information and when they do it may be conveyed wrongly in an attempt to discourage it. People with an ID may also lack the private and safe place to engage in sexual activity. The point to be made is that there appears to emerge a composite arrangement of institutional practices such as staff, parental and societal attitudes; barriers such as poor sexual education and knowledge and the issue of sexual abuse (Carlson et al. 2000) that will impact on whether people with an ID will have a sexual relationship and whether it will be positive or negative.

The researcher understands that when conducting a descriptive phenomenological study, construction of a literature review is completed after data collection and analysis is obtained. However, in keeping with the research guidelines of this proposed study, the researcher is obliged to carry out a literature review before any data dissemination will be done.
In keeping with Parahoo’s (2006) definition of a literature review, this paper will present an evaluation of the body of knowledge surrounding sexuality and the sexual experiences of people with an ID as a means to identifying issues in the literature that may necessitate future empirical attention. The most salient themes emerging from the literature include sexual experience and knowledge of people with an ID, barriers to sexual expression, attitudes of parents and attitudes of staff. Searches of electronic databases such as Proquest, Wiley InterScience and Cinahl will be used given their scientific relevance to nursing. Inclusion criteria were peer reviewed articles written in English, dated 1997-2010. 30 articles were retrieved and utilised.

The decision to carry out this proposed study has been largely influenced by the researcher’s own personal experience of working with people with an ID. A very vivid picture as emerged which shows that despite advocating the rights for people with an ID, there appears to be a professional reticence in recognising the sexual rights of people with an ID. Nurses are trained to observe, listen and support the biopsychosocial needs of people in their care. It is hoped that this proposed study can assist in liberating the descriptive stories and voices if people with an ID as it relates to their sexual experiences which may have been hitherto denied.

Sexual knowledge and attitudes of people with an intellectual disability

The attitudes and knowledge of people with an ID bears acute relevance to their quality of life (Galea et al. 2004). The very nature and design of support needed by people with an ID may be established through an examination of their sexual knowledge and attitudes. Research is consistent that individuals with an ID have inaccurate sexual knowledge and misconceptions compared with the general population (Servais 2006). Reports from sex therapist cases show that people are also told untrue dangers so that they may be afraid of sexual expression (Hinsburger & Tough 2002). McCabe (1999) showed that people with an ID experience lower levels of sexual experience, have stronger sexual needs and more negative attitudes to sex than people with a physical disability. Deficits in knowledge related to contraception, menstruation, pregnancy and sexually transmitted infections (STIs). Poor sexual knowledge was correlated to low sexual activity and inadequate sexual education. Sexual knowledge clearly has an important role to play in capacity to consent to sexual activity (McCabe 1999).
Garwood & McCabe (2000) measured both knowledge and attitudes of 6 men with a mild ID after they had received sexual education. Using the Sexuality, Knowledge, Experience and Needs Scale for People with ID (SKEN-ID) subjects were assessed in matters relating to dating, intercourse, dating and marriage. Findings indicated that post-education, subjects remained resistant towards hugging with no clothes on, marriage, masturbation, oral-genital sex, and parenthood. The researchers concluded that rather than being client led, content of sexual education programmes are often service led. Participants in the Kelly et al. (2009) also found that of the five women who received sexual education, only two received it through a structured format. Information trended also to be functional in relation to protection and menstruation and did not cover topics such as procreation or intercourse. Lesseliers & Van Hove (2002) in a phenomenological study observed that the knowledge of 46 people with an ID was rudimentary, with an understanding of the functions of genitals to be nonexistent, and only a few subjects knowing how children are conceived.

McCabe (1999) also found that despite greater sexual needs, people with an ID held very conservative attitudes towards sexuality. This is consistent with a study conducted by Lunsky and Konstantareas (1998) who found that those with an ID endorsed more negative attitudes towards homosexuality, pornography and masturbation compared to a non-ID sample. Both studies revealed that negative attitudes may also have been borne out of the adoption of repressive attitudes by staff towards the sexual experiences of subjects which in turn greatly diminish people with an ID asserting their desires. Lesseliers (1999) asserts that this unjust situation places people in a suppliant role that should be regarded unfitting for an adult.

**Barriers to sexual experiences**

Lesseliers (1999) puts it well when stating that care agencies and parents define and construct the sexual boundaries of people with an ID based on their own preconceived ideas. Many service providers and parents concede to the theoretical right to sexuality but very often only respond to it when sexual problems can no longer be ignored. People with an ID are also very dependent upon their environment in relation to learning, with that environment being extremely ‘present’.
Lessiliers and Van Hove (2002) found that participants indicated that despite the desire to form relationships/marriage they felt unsupported in this. Respondents commented that they did not engage in sexual activities due parental disapproval or internalising that sex was ‘dirty’. Servais et al. (2002) in a Belgian study found that the material environment in which people with an ID live is structured so that privacy to engage in sexual activity is prohibited. Participants felt that despite a desire for intimacy, ‘iatrogenic factors’ such as restrictive and controlling environments which lack privacy created a barrier to sexual expression. McCarthy (1999) comments that people with an ID may be forced to masturbate, remove their clothes in public or use their bodies as a weapon in an attempt to gain control over their lives. This in turn creates a punitive response, with them being withdrawn from such an activity (Wheeler 2001).

In relation to sexual health matters, Rodgers (2001) found that women with an ID had very negative experiences of menstruation and limited knowledge concerning menstrual care. This resonates with findings from McCarthy (2001) who found that women with an ID also had no understanding of what the menopause was or what changes it would bring. Ditchfield & Burns (2004) therefore strongly argue that in order for people to have mastery and self-determination in relation to sexual health and sexual matters that must be offered a good knowledge base.

Yacoub & Hall (2008) explored the sexual lives of men with a mild ID employing narrative interviews focusing on sexual behaviours and attitudes. Participants stated that attitudes provided by services seem to be moving away from benign paternalism to a more positive approach. Both Evans et al. (2009) and Lofgren-Matheson (2004) in studies respectively found that respondents felt positive about forming relationships, kissing and marriage.

**Attitudes of parents**

In a narrative review of the literature surrounding attitudes towards sexuality and ID, Anuos and Feldman (2002) found that parents still hold ambivalent and resistant attitudes towards sexuality for their children in the areas of marriage and procreation. This is supported by Cuskelley & Bryde (2004) who conducted a quantitative study measuring the attitudes of a sample of parents, staff and from the community. Results indicated that parents had the most restrictive attitudes which may have been due to the fact that they
were chronologically older than the other samples. Generalisability of findings may be difficult to apprehend given that all participants were female. A correlation between higher dependencies predicted less positive attitudes among parents, a finding consistent with many studies (Wolfe, 1997; Katz et al. 2000).

Evans et al. (2004) collected data using five focus groups comprising of people with an ID (of various gender, degree of ID and ID), parents of people with an ID and support staff. Focus groups have the advantage of generating in depth dialogue which may be gathered simultaneously towards a circumscribed topic (Polit & Beck 2010). Findings show that parents were content for their children to engage in non intimate relationships but that a sexual relationship would not be supported. Brown (1994) suggests that parents struggle to normalise sexual patterns when their child reaches sexual maturity and as such try to keep them in a state of suspended adolescence due to the generalised anxieties.

This is contradicted by Karalleou (2003) who conducted a quantitative study using the Greek Sexuality Attitudes Questionnaire-Learning Disabilities-Parents (GSAQ-LD-PARENTS). Karalleou (2003) found that there was little difference between parents attitudes towards human sexuality and sexuality of their own child indicating that parents invite the idea that sexual education would benefit their children and locate them in a ‘normalized ’pattern of sexual development.

**Attitudes of staff and service providers**

Gilmore & Chambers (2010) assert that the potential to realise normalised patterns of sexual experience for people with an ID may be influenced by the community and support staff. Grieve et al. (2004) examined attitudes drawn from samples from three types of residential units consisting of in-patient hospital units, larger residential units, and smaller community houses. Results show that generally all respondents exhibited a conservative attitude in relation to kissing or holding hands. The most significant attitudinal difference was between staff from smaller houses and larger homes. It may be inferred that in larger units people with all levels of disability are still treated like a heterogeneous group. The negative attitude held by nursing staff may be due to ‘the spread phenomena effect’ which points to the power that one attribute has in evoking inferences concerning all other attributes of that person (Wright 1983). Findings surrounding negative attitudes of staff are consistent with findings from Holmes (1998). Even though staff from the smaller units
endorsed positive support for sexual expression, all samples demonstrated a clear
resistance to homosexuality among male individuals.

This divertive feeling towards supporting homosexual relationships is resonates with a
qualitative design carried out by Yool et al. (2003). Respondents showed positive attitudes
towards kissing, hugging and masturbation in private but when it came to clients having
control and responsibility to enter a relationship, attitudes became less liberal. An obvious
concern gleaned by the researchers and one that was found in studies by Grieve at al
(2008) and Christian et al. (2002) was that the majority of staff was not aware of current
sexual policies. Christian et al. (2002) study showed that despite staff having positive
attitudes in supporting the psychosexual needs of women with an ID, only 71% of
respondents had received any formal sexual education training. Sexual education training
is invaluable in that it may mean a re-evaluation of their own acceptability judgements and
eliminate benign paternalistic transferability of incorrect sexual messages (Blanchett &
Wolfe 2002). Healy et al. (2009 find that this may mean that staff is responding to sexual
activities in an ad hoc manner that contravenes existing policy.

Drummond (2006) conducted a quantitative and descriptive pilot study measuring the
attitudes of parents and support staff towards sexuality and ID from a rural and urban day
centre from one large service provider in Southern Ireland. Findings indicate that carers
show more liberal attitudes than parents but attitudes were dependent on certain
contributing variables. Younger staff members and greater educational qualification
predicted permissive attitudes. The most relevant factor was religiosity. This is consistent
with a study by Healy et al. (2009).

Level and aetiology of intellectual disability may also be decisive factor in to how attitudes
may be constructed by support staff. Wolfe (1997) conducted a triangulated study using a
purposive sample of teachers and school administrators. Findings illustrated that tolerant
attitudes were evident towards relationships in people with a mild or moderate ID, but that
the practice of sterilization in people with a severe ID may be advocated This clearly
implies that negative attitudes are still configured around capacity and if a person with an
ID has the capability to exert and control over their sexual and reproductive issues. Klatz et
al. (2000) found a hierarchy of attitudes to exist with findings showing that despite
recognising that people with an ID had equal sexual needs to people with a physical
disability, participants held that people with an ID had less responsibility and control over sexual activity and less autonomy over whether they could develop a relationship. Lofgren-Marthenson (2004) conducted an ethnographic study using participant observation of people with an ID attending a dance. Interviews were also conducted with parents and staff in order to solicit attitudes towards behaviours. Findings show that male carers were more liberal than female carers in relation to the sexual expression of men with an ID. McCabe (1999) advises that this may have implications in relation to the content of sexual education and how it may be transferred. Patterns of a normalized sexuality are heavily inferred to be influenced by carers and that they may have become the “new obstacles or institutional walls” (2004, p. 206).

CONCLUSION AND RESEARCH PROBLEM

This literature review has examined four of the most salient themes emerging from the literature in relation to the sexual experiences of people with an ID. The first theme explored knowledge and attitudes from the subjective accounts of people with an ID and findings indicate that knowledge attitudes remain negative as they appertain domains of sexual activity such as masturbation, marriage, procreation and homosexuality. Findings may be as a direct result from filtering of misinformation or the controlling influence of parents and carers in their lives. Brown (1994, p. 142) puts it well when averring that for people with an ID “living an ordinary life is a challenge but living an ordinary sexual life is to live a life of defiance.” The second theme looked at structural barriers such as lack of privacy which may prohibit people with an ID from engaging in any sexual activity at all or indeed lead to the internalisation that prohibition implies sex something impure.

The third theme looked at parental attitudes with research showing parents seem to have deeply held restrictive attitudes particularly as it relates to their children entering a relationship or becoming parents. All parents wish to protect their children from potential harm that sexual maturation brings and parents of children with an ID should not be judged anymore harshly for this Wolfe & Blanchett (2002). The corollary of this may mean keeping their offspring in a state of suspended adolescence (Brown 1994), which in turn denies any possibility of forging intimate relationships. There clearly is a pressing need for education programmes aimed at parents so that it may support them in their new transition and offer psychosexual support to their children. The final theme focused on attitudes from
support staff. Attitudes are largely determined by age, degree and aetiology of disability and the environment in which staff work. More significantly, consistent across most of the studies was the summation that despite espousing theoretical sexual support for people with an ID, staff either supported clients in an ad hoc manner or refused to do it in fear that they were promoting risky behaviour.

RESEARCH QUESTION

AN INDEPTH EXPLORATION INTO THE SEXUAL EXPERIENCES OF PEOPLE WITH A MILD OR MODERATE INTELLECTUAL DISABILITY.

AIMS AND OBJECTIVES

Aim
The aim of proposed study is to explore the sexual experiences of people with a mild or moderate ID as it has occurs in their everyday lives.

Objectives
- To explore the sexual experiences of people with a mild or moderate ID
- To ascertain whether sexual education/knowledge affects nature of experience
- What factors have inhibited or facilitated their sexual experiences
- Pursue recommendations for future practice and policy making
CHAPTER TWO

Introduction
This chapter will present an evaluation of the research methodology for the proposed study. A descriptive phenomenological qualitative design will be used to gather a more in depth contextual understanding of the sexual experiences of people with a mild or moderate intellectual disability (ID). A purposive sample of six individuals with a mild or moderate ID will be used. Data collection will be obtained through the application of semi-structured interviews. Dissemination of data will be treated using Colaizzi’s (1978) evaluative framework for phenomenological analysis. Methodological qualitative rigour will be discussed as it is seen through key qualitative research concepts, namely trustworthiness; reflexivity; confirmability, and transferability. Finally, a pilot study and ethical considerations will be discussed.

Research design/methodology
Parahoo (2006) states that a research design is a plan that specifies who, where and when data are to be collected and analysed. Burns & Grove (2009) add by asserting that an appropriate design must be chosen that is commensurate with the topic investigated in order to answer the specific aims and objectives that the research question poses. A research design can be qualitative or quantitative in nature (Cormack 2000) both of which are guided by divergent philosophical, paradigmatic and methodological traditions. Quantitative research is largely a controlled and systematic process (Polit & Beck 2010) aimed at producing empirical analysis of a topic of interest that may be generalised to a larger population (Parahoo 2006). The researcher is orientated towards a qualitative position in exploring the sexual experiences of people with a mild or moderate ID which provides rich, subjective accounts of a phenomenon of interest as it occurs within its natural environment (Munhall 2007). The context in which a person describes/experiences an event is central to qualitative research (Munhall 2007) and as such does not attempt to generalise findings in the manner that quantitative research does. The researcher also finds that qualitative methods and findings can emulate the art of nursing practice (Broeder & Donze 2010, p. 197) where a holistic understanding of people occurs.

This study proposes to make a case for a qualitative approach that is a descriptive phenomenological design. Rooted in a philosophical tradition, phenomenology is a way of examining people’s lived experiences to ascertain critical truths about reality and study
phomena which are subjective to individuals (Polit & Beck 2010). Descriptive phenomenology as developed by Edmund Husserl (1859-1938) is the unbiased study of things as they appear so that an essential understanding (essence) of human consciousness and experience may be arrived at (Dowling 2007). For a phenomenological description of the “life-world” (Lebenswelt) to be made, phenomenological reduction (epoche), description, and a search for ‘essences’ must be undertaken (Dowling 2007). Stake (2010) states that all past and existing knowledge of the outer world and presenting phenomenon must be held in abeyance or ‘bracketed’ leaving it neither denied nor confirmed. Husserl’s phenomenology is descriptive (eidetic) where essences, structures, relations are found through bracketing (Stake 2010).

The researcher will seek to ‘bracket’ their own views in describing the sexual experiences of people with an ID rather than interpreting data as espoused by Heideggerian phenomenology (Stake 2010). The researcher does not find that interpretation and analysis of experiences as it explored through the researchers own experience and knowledge to be a good ‘fit’ for this study. The researcher has also chosen Husserlian phenomenology because it does not require a first hand, in depth knowledge of the data under investigation while still allowing for a realistic descriptive story of the individuals experiencing it.

**Population/Sample**

A population in research refers to those elements that make up the focus of the study that fit fixed criteria (LoBiondo-Wood & Haber 2010). A sample according to Gerrish & Lacey (2010) is a subset of a target population, normally defined by the sampling process. A small sample of ten people with a mild or moderate ID will be used, so that each description of sexual experiences is examined in depth. Munhall (2007) notes that the advantages of a small sample size means that a good rapport can be built between researcher and subjects and may solicit more authentic responses. The researcher has chosen to use non-probability or purposive sampling which is predominantly used in qualitative research (Parahoo 2006). Purposive sampling involves the researcher selecting individuals who will have knowledge of the phenomena studied or deemed potential information rich cases (Mapp 2008). The researcher will therefore place a poster (Appendix 8) in a training centre that people with a mild or moderate ID attend on a daily basis. Details of the proposed study will be given with the researcher’s mobile number and email address given so that respondents may contact them. The researcher will also seek
authorization from the employers and Directors of Nursing (Appendix 7) in gaining access to the training centre.

The establishment of exclusion and inclusion criteria according to LoBiondo-Wood and Haber (2010) increases the precision of a study and strengthens evidence produced. For the proposed study the characteristics that participants will be require

- People with a mild or moderate intellectual disability as defined by the International Classification of Diseases (ICD-10) (Appendix 12)
- People attending a training/employment agency
- People who can communicate verbally and possess literacy skills

Exclusion criteria include:

- People with a severe or profound ID as defined by the ICD-10 (Appendix 12)
- People with non-verbal skills
- People living in residential care
- People under the age of eighteen years

Data collection

Qualitative research employs methods which allows researcher to collect data surrounding the ‘emic’ or lived experiences of people (Polit & Beck 2010). This is made permissible through a number of data collection strategies such as interviews, focus groups, action research and observation (Parahoo 2006). van Teijlinjen & Ireland (2003) state that when applying Husserlian phenomenology to research, the optimum way of collecting data is through one-to-one interviews. Charmaz (2006) posits that interviews are a powerful vehicle where discovery of people’s ‘life-worlds’ can be realized by exploring metaphors context and meanings of unique experiences. There are three different types of interviews; structured, semi-structured and un-structured (Banner 2010). Structured interviews involve the use of a set of questions with a range of predetermined answers or questionnaires with the researcher adhering strictly to the topic guide (Banner 2010). Unstructured interviews evolve like conversations, where the researcher and respondent are aware of the topic with no set responses (Baumbusch 2010). The researcher finds that the use of semi-structured interviews which are situated in the middle to be advantageous in that it allows the researcher to identify broad themes which will guide the interview
process while at the same time preserving flexibility in the pursuit of interesting leads and descriptions (Charmaz 2006).

This researcher is reminded that in-depth interviewing is an inherently multifaceted and complex endeavour (Banner 2000). Therefore the researcher needs to foster an atmosphere that includes careful listening and the ability to interpret and observe what subjects are saying on many levels in order to offer a suitable response. Banner (2000) stresses that nurse researchers are endowed with special knowledge and skills in the research interview such as being a non judgemental and communicative agent. It is the expertise in practice that allows nurses, as nurse researcher to apprehend the wider implications of what respondents reveal in research. Topic questions will be formulated through the application of a Statement of Intent (Colaizzi 1978) (Appendix 11). Construction of statements will allow the researcher to uncover, probe and dissect their own hypotheses, biases, experiences surrounding sexuality. This then will offer a preliminary basis in which the research interview questions will be formulated (Colaizzi 1978). Further clarity surrounding construction of the final questions may be expanded through the use of a pilot study which allows comparison of the researcher’s presuppositions and those of others. A pilot study may be described as a small scale or trial run of the larger study. It is used to assess the feasibility of a study, eliminate any potential problems and refine any methodological errors (Polit & Beck 2010). The researcher will also use the pilot study as a means to testing the audio-recording equipment and assessing the suitability of the interview room.

The researcher will avoid the use of leading questions or jargons which may contaminate or skew data (Baumbusch 2010). The researcher will chose a neutral, confidential and non-judgemental environment to conduct the interview where subjects can talk freely in an unhurried and open way. The interviews will audio taped and transcribed verbatim which will preserve accuracy, minimise disruption to data collection and maintain researcher focus.

Data Analysis
In order to provide an in depth description of the essential structure of the sexual experiences of people with an ID, Colaizzi (1978, p. 59) framework of analysis will be utilised (see appendix eleven). This is in keeping with the tenets of Husserlian descriptive phenomenology (Koch 1996). Holloway & Wheeler (2009) state that based on the stream
of phenomenology used, that is, hermeneutics or Husserlian, will guide the researcher as to the most applicable framework of data analysis. Polit & Beck (2010) posit that data analysis in qualitative research typically starts with seeking the establishment of recurrent themes by using a framework. The most important aspect of Colaizzi’s method is that validation of the study must be offered and verified by the respondents who have given a description of their sexual experiences (Mapp 2008).

The audio-taped interviews will be transcribed verbatim according to Colaizzi’s guidelines. A protocol (or each individual transcription) will be read repeatedly in order to ascertain a sense of the entire content. All tapes will be duplicated in case of loss and will be stored in accordance with the Data Protection Act (2003). The researchers mentor will read and listen to the data and with their phenomenological experience will prevent inaccuracies. All similar themes will be categorised and given a title. In keeping with the process of bracketing in phenomenological research, the researcher will place all existing assumptions and biases in abeyance, so as not to influence data.

**Methodological Rigour**

Findings of this proposed study must be an authentic and trustworthy reflection of the description of sexual experiences that people with a mild or moderate ID give. Rigour according to Gerrish & Lacey (2010) refers to how strong a body of research is in terms of confirming that all procedures have been followed judiciously, that all potential confounding factors have been removed and that the reader judges conclusions to be dependable or trustworthy. Put simply, the concept of ‘goodness’ of research or its trustworthiness is a way in which the competence, transparency and integrity of that research is shown (Tobin & Begley 2004). For the proposed study the researcher will use a framework developed by Lincoln and Guba (1985) as cited in Parahoo (2006) that seeks to establish methodological rigour in qualitative research. These include credibility, transferability, dependability, confirmability and authenticity.

Credibility seeks to address the issue of ‘fit’ between participants accounts and how the representation of them by the researcher (Koch 2006). The researcher intends to confirm whether congruence exists between what participants described and what was transcribed through member checking, prolonged engagement, and an audit trail. The issue of member checking will be used where the researcher will return to participants and consult with them as to whether descriptions given were authentic. Another strategy used in assuring
credibility, and one that is part of the repertoire of skills of nursing is that of self-awareness. This researcher will use a reflexive field journal where all prejudices and biases will be ‘bracketed’ that will hopefully promote honesty and transparency. Reflexivity according to Northway (2000) may be viewed as the critical gaze turned toward itself. The researcher will use prolonged engagement, which means that this researcher will put satisfactory allocated time in collection of data affording a richer breath of knowledge of the sexual experiences of people with an ID. This will also enhance credibility.

Dependability concerns itself with the responsibility of researchers to substantiate that every part of the research is transparent, methodical and clearly documented (Tobin & Begley 2004). The author proposes to develop an audit trail where external reviewers can view its dependability, as opposed to consistency, through a discussion of methodological and analytical decisions throughout the research (Koch 2006). This also strengthens the confirmability of the proposed study with subjects understanding that the data produced is not exaggerated or fabricated by the researcher.

Transferability/fittingness as opposed to applicability of a study, means that a body of research’s findings can ‘fit’ into other contexts outside the study situation and when readers regard findings as meaningful and find it applicable within their own contexts and experiences (Koch 2006). The researcher proposes therefore to furnish enough descriptive data in the proposed study so that others may evaluate the applicability of data to other contexts and settings.

**Pilot Study**
A pilot study will not be used for this study. It is understood by the researcher that pilot studies inform the novice researcher about what the study will curtail but for descriptive phenomenological studies, each narrative is unique and the same results will not be achieved each time unlike in quantitative studies which aim to yield the same results each time, thus achieving a valid or reliable method. The researcher will attempt the pilot the methods used, such as audio-taping and building confidence in speaking and building rapport without building bias.

**Ethical Considerations**
Research is viewed as a scientific human endeavour that is organised according to a range of protocols, methods, guidelines and legislation (Gerrish & Lacey 2010). Research ethics
is that domain of enquiry that identifies ethical challenges with a view to developing guidelines that safeguard against any harm and protects the rights of human subjects in research (Rogers 2008). This has been an explicit requisite for research since the development of The Nuremburg Code and Declaration of Helsinki (1964) (World Medical Association 2008). The researcher is cognisant that the issue of sexuality is a sensitive and private matter and as such has an ethical responsibility to adhere to key ethical principles such as respect, informed consent, beneficence, non-maleficence, veracity and justice. Ethical approval will be obtained from the affiliated hospital (Appendix 7) and university (Appendix 6).

Informed consent is the cornerstone of ethical research (Casssell & Young 2002), and important aspect of this is the quality of information provided to potential subjects. The researcher will provide the subjects with an information sheet detailing all information about the research process in a clear and concise manner with a personal explanation if required (Appendix 9). A consent form will be given (Appendix 10) with subjects retaining the right to assent voluntarily and free from exploitation and coercion. This will further enhance the subject’s right to self-determination and autonomy. Forms will be locked in a press of which the researcher will have sole access as admonished by the Data Protection Act (2003). Recognising that subjects may have never being part of research before, the researcher will incorporate a process of ongoing consent or “process consent” (Dalton & McVilly 2004) which means that at every phase of the interview session the subject’s involvement will be renegotiated. This also implies that the subjects are free to withdraw from the study at any point (WMA 2006). In the event that subjects seek further clarification about the study the will be encouraged to consult with a confidant or independent advocate.

The subjects will have a right to withdraw from the research free (WMA 2008) and this will be made explicit on the information sheet and verbally reiterated at the time of the interview. The ethical principle of non-maleficence implies that no harm should come to participants (Cormack 2000). The researcher will therefore be mindful that the interview could bring up painful and negative memories. In this instance the researcher will constantly assess levels of stress, offer subjects debriefing sessions or recourse to specific counselling should this be needed. The right to confidentiality is essential in research (Polit & Beck 2010) but may be conflicting in this proposed study. This is due to the facts that interviews concerning sex may lead to potential disclosure of abuse or similar
circumstances may lead the researcher to break confidentiality. However, the researcher will protect the respondent’s identities and responses from the public domain. Assurances that identities of subjects will be concealed will be through the assignment of pseudonyms in data analysis and throughout discussion in the study. Encryption technology will be used so that electronic data is kept safe; this is in keeping with the Policy on Good Research Practice (Trinity College 2009). Respondents were also advised that when their interview was recorded, transcripts would be anonymous and copies of transcriptions returned to them if requested. In relation to ensuring that respondents are shown fair treatment and justice, each individual will be treated equally without judgement or prejudice.

The principle of veracity or truth telling (Cormack 2000) is inherently important and the researcher will show this by telling the subjects the aim of the research and proposed outcomes. Finally, as the predicated on the ethical principle of beneficence, the researcher will strive to maximise the benefits that this study will be to people with an ID and the ID discipline and community.
CHAPTER THREE

Chapter two is concerned with the results that the researcher feels will be achieved throughout this study. The outcome of the study is proposed along with the anticipated dissemination, cost and time scale.

PROPOSED OUTCOME OF THE STUDY

It is expected that this study will reveal the sexual experiences of people with a mild or moderate ID as told from their own narratives of their everyday lives. This study will ascertain the sexual knowledge of the participants which affect their experience and show the system of education for these individuals. The study may also unveil the things that have affected their sexual experiences also.

DISSEMINATION

The results from this study can be used to make recommendations for future practice and policy development. These findings will be unique accounts from persons with ID, whom should be at the forefront of policy making and practice. These findings will be published by PUBLICATION X who will accept studies carried out by novice researchers. I will require the expertise and knowledge from a research mentor or facilitator to review my study before submission. The expected audience are service providers, people who support individuals who have intellectual disabilities and family members of persons with intellectual disabilities. The findings may also encourage further studies in the area.

TIME SCALE

The anticipated time that it will take for this study to reach dissemination is 18months. A Gantt chart, compiled in Microsoft EXCEL is displayed in appendix one to show the proposed time scale.
RESOURCES
Appendix two shows the expected resources that will be needed to complete this study successfully. This study requires a lot of correspondence due to sensitive issues surrounding consent and gaining access to the training centre. This may accumulate costs of up to 400 euro. A room is necessary to interview the participants, preferably on campus to complement the creation of a relaxing familiar ambience. It is possible that the service will provide a room to carry out the study but at this time with cutbacks, it could be possible that they will apply a charge. At a guess, to interview ten individuals at one hour at a time, it may cost 50 euro per hour, accumulating to 500 euro in total. The accumulated costs for data collection will come to at least 200 euro. Travel expenses will come to at least 200 euro also as the training centre is 20 minutes away from my home. The cost of transcription and secretarial equipment will be 200 euro and unforeseen circumstances have been afforded 500 euro.

CONCLUSION
This study proposes to add to the body of literature and may be submitted to a publisher for publication. Then it will be targeted at people who support individuals with intellectual disabilities, service providers and family. This will inform policies and practice. The study will last eighteen months. The accumulated cost of this study will be 2,000 including correspondence costs, travel expenses and data collection equipment.
REFERENCES


APPENDICES
APPENDIX ONE

Time Scale

- Meeting with ethics committee TCD
- Literature review
- Methodology
- Ethical approval from TCD
- Ethical approval from service
- Sample
- Establish rigor and trustworthiness
- Inviting participants
- Data collection
- Data analysis
- Preliminary report
- Final report
- Submission
- Dissemination
# APPENDIX TWO

<table>
<thead>
<tr>
<th>Resources</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Correspondence: stamps, letters, envelopes, phone calls</td>
<td>400</td>
</tr>
<tr>
<td>Renting a room: 50 euro per hour, 10 individuals for 10 hours</td>
<td>500</td>
</tr>
<tr>
<td>Audiotapes and Audio-machine</td>
<td>200</td>
</tr>
<tr>
<td>Travel expenses</td>
<td>200</td>
</tr>
<tr>
<td>Transcription costs for pens and papers</td>
<td>200</td>
</tr>
<tr>
<td>Unforeseen costs</td>
<td>500</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>2,000</strong></td>
</tr>
</tbody>
</table>
APPENDIX THREE

Statement of Intent

The researcher recognises that in order to facilitate the construction of interview questions, they must tease out their own sexual experiences, judgements, beliefs, attitudes and behaviours. This will form the preliminary basis of what the content of interview questions will be.

What did I think about sex before I ever had it? *I thought that it was going to hurt.* *My mother made me think that sex before marriage was wrong and that she would disappointed if I came pregnant. I was terrified about reaching menarche. I didn’t enjoy my first experience. I felt pressure to have sex by a certain age from my peers.*

Guilt surrounding masturbation. *I always felt guilt around masturbation and never admitted to anyone that I did it because I thought no other women did it.*
APPENDIX FOUR

Topic guide

Do you have a boyfriend/girlfriend?
Do you meet each other often?
What do you do when you meet your girlfriend/boyfriend?
Has anybody ever talked to you about sex before now?
Prompts (if necessary): Like what?
    When, how, with who?
Have you had sexual intercourse?
Prompts: Tell me about it?
    Is there anything else you’d like to talk about?
What do you think about masturbation?
Prompts: Can you tell me more?
Ms Bloggs,
Chairperson
Ethics Committee,
Training centre X,
Dublin 99
08/07/10
Re: An in-depth exploration into the sexual experiences of people with a mild or moderate intellectual disability
Dear Ms. Bloggs,

I am carrying out a phenomenological exploration of the lived experiences of people with a mild or moderate intellectual disability as part of my BSC in intellectual disability nursing studies with University X. By carrying out a review of the literature, I found that there is very little research looking at the descriptive narratives as told by persons with intellectual disabilities. I expect that this study will bring light to these narratives and these will inform practice and policy making.

The sample of participants will be six persons with mild or moderate intellectual disabilities. I will use semi-structured one-to-one interviews and will tape these interviews to analyse the data collected. I have worked with individuals with intellectual disabilities for the last twelve years in residential services and day centres and have excellent communication skills.

Please see my stamped addressed envelope and research proposal enclosed as a hard copy and an e-copy. You can view my ethical considerations in chapter two and copies of the letter to the director of services, the poster I would like to display to attract participants, the consent letter, information sheet, my statement of intent and the topic guide in the appendices of the proposal.

Please contact me if necessary. Thank you for your time,
Yours sincerely,
Mr Somebody,
Chairperson
Ethics Committee,
University X,
Dublin 66
08/07/10
Re: An in-depth exploration into the sexual experiences of people with a mild or moderate intellectual disability

Dear Mr. Somebody,

I am carrying out a phenomenological exploration of the lived experiences of people with a mild or moderate intellectual disability as part of my BSC in intellectual disability nursing studies, which will need collaboration with Training centre X. By carrying out a review of the literature, I found that there is very little research looking at the descriptive narratives as told by persons with intellectual disabilities. I expect that this study will bring light to these narratives and these will inform practice and policy making.

The sample of participants will be six persons with mild or moderate intellectual disabilities. I will use semi-structured one-to-one interviews and will tape these interviews to analyse the data collected. I have worked with individuals with intellectual disabilities for the last twelve years in residential services and day centres and have excellent communication skills.

Please see my stamped addressed envelope and research proposal enclosed as a hard copy and an e-copy. You can view my ethical considerations in chapter two and copies of the letter to the director of services, the poster I would like to display to attract participants, the consent letter, information sheet, my statement of intent and the topic guide in the appendices of the proposal.

Please contact me if necessary. Thank you for your time,

Yours sincerely,

_______________________
Ms Herself,
Director of Service
Training Centre X,
Dublin 99
08/07/10
Re: An in-depth exploration into the sexual experiences of people with a mild or moderate intellectual disability
Dear Ms. Herself,

I am carrying out an exploration of the sexual experiences of persons with mild or moderate intellectual disability and would like to put a poster up in the training centre so that I may interview six willing applicants about their sexual experiences. The study will use phenomenological inquiry with descriptive data analysis and unstructured interviews.

Please the research proposal enclosed in a hard copy and an electronic copy for your viewing. This includes a literature review, full description of methodology, proposed outcome, budget and timescale and a list of appendices. These include copies of letters to ethics committees, both academic and the training centre itself, consent form, information sheet, poster, statement of intent and topic guide for the interview.

Thank you for taking for your time. Please contact me for further information,

Kind regards,
Yours sincerely,
A STUDY ABOUT SEXUALITY

HOW DO YOU FEEL ABOUT SEX?
WHAT ARE YOUR EXPERIENCES?
WOULD YOU LIKE TO MAKE YOUR SERVICE BETTER?

My name is ______ and I’m doing a study of the sexual experiences of people with intellectual disability. I want people to know what you think!

If you are over 18 and would like to give your experiences for this study, contact me at _______
*Participants for this study must have the capacity to consent in partaking in research. Please consult your team leader for guidance and information regarding this study.

APPENDIX NINE

Participant Information Letter (in Plain English)

An in-depth exploration into the sexual experiences of people with a mild or moderate intellectual disability

- **My name is _____** and I am a student doing my intellectual disability nursing degree in University X. I need your help for this research but you must be over 18 and have a mild or a moderate intellectual disability, you must be attending a training centre, you must be able to tell your own story and you must be able to read and write. You must not live in residential care.

- I want to **interview you on your own for one hour.** You have to fill in a “consent” form before the interview. You can ask your family, friends or team leaders for advice on this. You can stop at any time and you won’t get into trouble for this. It is up to you if you would like to keep going with the study and I will ask you if you want to keep going.

- You will be **asked if you are in a relationship** and what your sexual experiences have been. The interviews will be **tape recorded** and will be **put into words** which you can see anytime you like. I will send them to you before I complete it. The results may be **published to a journal** so that other others who support people with intellectual disability can see what you have to say.

- **The good things that can happen with research:** Training centres and other services can learn how to respect people with intellectual disability and their rights. People with intellectual disability have a say

- **The bad things that can happen with research:** You may become upset by some of the topics that come up or may feel like you need to talk about this. I am not a counsellor but I will help you to contact one. You do not have to answer any question that you don’t want to.

- **Confidentiality:** everything you tell me in the interview will be secret between me and you and your name and other details will not be used. However, if you tell me something that is very serious, like somebody is in trouble, I may have to tell someone. Everything used in the study, including the audiotapes will be kept safe and private.
This study is insured so your rights are safe.
The researcher can stop the study at any time too.
I have asked the training centre and the university for permission.

For Further information contact me at _______

APPENDIX TEN

Consent Form

CONSENT FORM

Read this. If you agree then you can sign.

I (please print name) ______________________________ give my consent
to take part in this study.

1. I have read the information sheet I understand. I know that I will answer questions about my sexual experiences.
2. I know that everything I say is between me and the researcher but if there is something very serious, such as the harm of somebody or me, then the researcher will have to tell somebody. My name or personal information is private and will not be used. The information and audiotapes will be kept safe and only the researcher will see the interview information and audiotapes. I can view them at anytime.
3. I volunteer freely to be part of this study, without duty or obligation. I understand that I am free to withdraw from this study at anytime without notice or penalty. I have received a copy of this agreement.

Participant’s signature: ______________________________

Date: ____________________

Researcher’s name (in print): ______________________________

Researcher’s signature: ______________________________

Date: ____________________
APPENDIX ELEVEN

Colaizzi (1978, p. 59) Data Analysis Framework

1. Read each participants narratives or protocols to acquire a sense of them.
2. Go back to the protocols and take from them the phrases that relate to the phenomenon under study.
3. Formulate meanings of the sentences/phrases taken from the protocols- the researcher uses “creative insight” to take meaning from what the participants say.
4. Organise each meaning into theme clusters which can then be categorised.
5. The results are then put together into an “exhaustive description” of the phenomenon.
6. “An effort is made to formulate the exhaustive description of the investigated phenomena in as unequivocal a statement of identification of its fundamental structure as possible” (p. 59)
7. In order to validate the study further, the researcher will bring the statement and exhaustive description back to the participants in an interview and ask the participants if this reflects their description of their experiences.
APPENDIX TWELVE

ICD-10 International Classification of diseases

The tenth addition of the World Health Organisations International Classification of Diseases (ICD-10) uses the following criteria for an intellectual disability:

A prominent impairment in cognitive functioning
A significant adaptive and social functioning impairment
Age of onset before 18 years (WHO 1996)