

**The effect of a sexuality training programme on the knowledge
and attitudes of caregivers working with women with
intellectual disabilities who live in residential care facilities:
A social story approach**

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Abstract

The sexuality of all women, including those with or without intellectual disabilities, embraces more than just the knowledge about body parts and sexual behaviour. Women's sexuality includes life experiences of appropriate and inappropriate touching, privacy and appropriate conversations, different types of relationships and competence in sexuality education. Therefore, sexuality is one way in which women define themselves, as it is an extension of self-esteem that can also influence interaction with others.

The main aim of this study was to describe the effect of a two-day, custom-designed sexuality and relationship education training programme by considering the policy system, the stakeholder system and the pedagogical system, in order to change the knowledge and attitudes of caregivers who are working within residential care facilities with women with intellectual disabilities positively. This will enable caregivers to view education and relationship building as an integral part of these women's lives. This study employed a three-phase mixed method research design. Phase 1 focused on the qualitative data obtained from focus groups ($N=30$) and how it informed the design and considerations of the training programme. Phase 2 focused on the development and pilot testing of the training programme ($N=20$). Phase 3 focused on the quantitative data and the main study, which involved a pre-test post-test group design ($N=31$), during which all participants were trained using the custom-designed training programme, aSeRT (Sexuality and Relationship Training Programme). Significant positive outcomes were shown after caregivers participated in the aSeRT within the results, when their pre-training and post-training mean scores were compared. The six participant variables (awareness of the sexuality policy at the facility; church attendance; work experience; whether they had spoken about sexuality to the women with intellectual disability before; their knowledge about whether women with intellectual disability had been exposed to sexuality training before; and their age) did not statistically impact significantly on their knowledge and attitude change. Satisfaction ratings were positive and participants commented favourably on the planning of the training, the training material and the method of training. The findings from this research provide recommendations on how further studies can continue to add to the existing body of knowledge, emphasising that sexuality education can be integrated with social stories for women with intellectual disabilities and implemented in other residential care facilities.

Keywords: attitude; caregiver; disability; education; intellectual disability; knowledge; relationships; residential care facility; sexuality; social stories; training programme

Opsomming

Die seksualiteit van alle vroue, insluitend diegene met of sonder intellektuele gestremdhede, behels meer as net kennis oor liggaamsdele en seksuele gedrag. Vroulike seksualiteit sluit die lewenskennis van gepaste en onvanpaste aanraking, privaatheid en toepaslike gesprekke, verskillende tipe verhoudings, en seksualiteitsopvoedingsvaardighede in. Daarom is seksualiteit een manier waarop vroue hulself definieer, aangesien dit 'n uitbreiding van hul selfbeeld is wat ook hul interaksie met ander mense kan beïnvloed.

Die hoofdoel van hierdie studie was om die effek van 'n 2-dag, doelontwerpte onderwys- en opleidingsprogram oor seksualiteit en verhoudings te beskryf, met inagneming van die beleidstelsel, die stelsel van belanghebbendes, sowel as die opvoedkundige stelsel, om sodoende die kennis en houdings van versorgers wat by residensiële sorgfasiliteite met vroue met intellektuele gestremdhede werk, te verander sodat hul seksualiteitsopvoeding en verhoudingsbou as 'n integrale deel van hierdie vrouens se lewens sal beskou. Hierdie studie volg 'n drie-fase meervoudige-metode navorsingsontwerp waarin daar in Fase 1 gefokus is op die verkryging van kwalitatiewe data uit fokusgroepe ($N=30$) en hoe om hierdie inligting te gebruik om die ontwerp van die opleidingsprogram te rig. Fase 2 het op die ontwikkeling en proeftoetsing van die opleidingsprogram gefokus ($N=20$), en Fase 3 op die kwantitatiewe data en die hoofstudie, wat 'n voor-toets na-toets groep ontwerp behels het ($N=31$) waartydens alle deelnemers opgelei is in die gebruik van die doelontwerpte opleidingsprogram, aSeRT (Seksualiteit en Verhoudingsopleidingsprogram). Resultate het beduidende positiewe uitkomst getoon vir versorgers wat aan die aSeRT deelgeneem het, toe hul voor- en na-opleiding gemiddelde tellings vergelyk is. Die volgende ses deelnemerveranderlikes, (naamlik bewustheid van die seksualiteit by die fasiliteit; kerkbywoning; werksondervinding; of hulle voorheen met die vroue met intellektuele gestremdheid oor seksualiteit gepraat het; hul voorafkennis oor of vroue met intellektuele gestremdheid voorheen blootgestel is aan seksualiteitsopleiding; en hul ouderdom), het nie 'n statistiese betekenisvolle impak op hul kennis en houdingsverandering gehad nie. Tevredenheidgraderings was positief en deelnemers se kommentaar was gunstig oor die beplanning van die opleiding, die opleidingsmateriaal en die opleidingsmetode. Die bevindinge van hierdie navorsing bied voorstelle van hoe toekomstige studies op die huidige kennis rakende seksualiteitsopvoeding kan voortbou en beklemtoon dit dat seksualiteitsopvoeding met sosiale stories geïntegreer moet word vir vroue met intellektuele gestremdhede en in ander residensiële sorgfasiliteite geïmplementeer kan word.

Kernwoorde: houding, versorger, gestremdheid, opvoeding, intellektuele gestremdheid;, kennis, verhouding, residensiële sorgfasiliteit, seksualiteit, sosiale stories, opleidingsprogram

CHAPTER 1

Orientation

1.1 INTRODUCTION

This chapter provides an orientation to the research and background information on the complex issue of sexuality and the importance of educating women with intellectual disabilities about this. It furthermore explains the purpose of the research as well as of the various chapters. Next, the specific terminology used in this thesis is defined. The chapter concludes by providing a list of all abbreviations used.

1.2 PROBLEM STATEMENT

Sexuality is a complex issue and encompasses fundamental aspects of who we are as human beings. As such, it forms an active and inseparable part of reaching our full potential as women, and is typically expressed in relationships with others. An increasing number of individuals with intellectual disabilities wanting to know more about their sexuality are engaging in intimate relationships and are requesting appropriate information.

However, in South Africa the reality is that many of these women with intellectual disabilities spend most of their lives in residential care facilities. Caregivers at these facilities find it difficult to address sexuality issues which manifest as social challenges and sexual missteps. Furthermore, sexuality is sometimes viewed as a taboo subject and few residential care facilities have appropriate sexuality policies. This creates challenges in caregiving when attempting to balance assistance with autonomy, protection with provision of rights, and sexual competence with capabilities.

These aspects complicate matters when offering training about sexuality to women with intellectual disabilities. However, sexuality cannot be ignored. The lack of training of and guidance to these women may contribute to misunderstandings and to socially inappropriate behaviour. The attitudes and knowledge of caregivers who have continuous contact and interaction with these women, impact on how guidance in terms of sexuality is provided. For example, if they have more conservative attitudes about the sexuality of women with intellectual disabilities and feel that sexuality is not an important topic they might brush it aside during caregiving. However, all women, including those with an intellectual disability, have the right and need to express their feelings related to sexuality. The right to be free from sexual exploitation and harm is

also of critical importance.

Social systems theory, which includes elements to develop a sexuality and relationship education programme for a population identified with an intellectual disability, provides a sound paradigm for the study. To be able to achieve this it is necessary to work within the caregivers' system in the residential care facility, as caregivers (the secondary stakeholders) form part of the context in which women with intellectual disabilities (the primary stakeholders) exist. Furthermore, caregivers must be able to recognise the potential for inclusion of this area of life for the primary stakeholder group, namely life and function. Acknowledging the caregiver's role within the systems theory and the understanding of the individual's experience of that system's interaction within their environment and with other systems is crucial in developing effective programming. This is because it can increase the quality of the interactions and relationships for these women with intellectual disabilities', making life more productive and satisfying.

1.3 CHAPTER OUTLINES

In Chapter 1, the problem statement is provided, and the significance and relevance of the study is highlighted. Chapter 1 also includes an outline of subsequent chapters, clarifies the terminology used and explains all of the abbreviations found in the thesis.

In Chapter 2, the social systems theory of sexuality is described, including various specific system levels. Firstly, the sexuality of women with intellectual disability is acknowledged, followed by a discussion of sexual identity. Next, sexuality needs as well as specific misconceptions are addressed before three different disability models are examined. Finally, the various stakeholders in the social systems theory, namely the primary stakeholders, the policy systems, the secondary stakeholders and the pedagogical system are highlighted.

In Chapter 3, the qualitative first phase of the research is described. It documents the planning and development of a sexuality and relationship education programme based on the guidelines suggested for policy development within a residential care facility. It also illustrates how three focus groups with different stakeholder groups contributed to the development of the programme. The programme was designed to encourage, facilitate and support caregivers within residential care facilities, who work with women with

intellectual disabilities to view sexuality education and relationship building as an integral part of these women's lives.

In Chapter 4, the complete development of the Sexuality and Relationship Training programme (aSeRT), which represents Phase 2 of the research, is described. This chapter commences with a description of the aSeRT, the aims of the training, the myths and misconceptions about sexuality and a brief overview of the training content and layout of the programme.

In Chapter 5, the research methodology used in the third phase of the research, the quantitative phase, is discussed. Firstly, the aims (including the main aim and sub-aims) are described, followed by a discussion of the research design. The development of the materials, specifically the measuring instrument, is then explained, followed by an in-depth discussion of the pilot study focusing on the objectives and procedures, with its results and recommendations for the main study. Finally, a description of the participants, the data collection procedures, the material and equipment used in the main study as well as data analysis, follow.

In Chapter 6, the results from the third phase (the quantitative phase) of the research are provided and discussed. This chapter specifically focuses on the last four sub-aims and compares the pre-test and post-test attitudes and knowledge of caregivers regarding sexuality and relationships. It includes the four themes covered in the aSeRT, namely appropriate and inappropriate touching, privacy and appropriate conversations, romantic relationships and different types of relationships, and sexuality education. Data are not only organised and analysed but also interpreted so that conclusions can be drawn regarding the effectiveness and usefulness of the aSeRT training in achieving specific outcomes.

In Chapter 7, a summary of the results from the three phases of the study is presented. This is followed by a discussion of the clinical implications of the results. A critical evaluation of the study follows, highlighting both the strengths and the limitations of the study. Finally, recommendations for further research are provided.

1.4 DEFINITION OF TERMS

Attitude

"Attitudes are a positive, negative, or mixed evaluations, of an object or concept that is expressed at some

level of intensity by using words such as like, love, dislike, hate, admires and detests" (Kassins, Fein & Markus, 2011, p.203). In this study, the focus is on caregiver's and the determination of their attitudes toward the sexuality of women with intellectual disabilities, as well as to ascertain and identify whether there is an association between caregiver attitude regarding sexuality and their perceived ability to participate in a sexuality education training programme.

Caregiver

"The role of a caregiver is all encompassing and involves a complete assumption of a range of responsibilities and activities that the individual with the disability is unable to perform independently. This may range from grocery shopping to all activities of daily living, and may vary from one day to the next depending to the extent of physical and/or mental disability" (Wood, 1991, p.195). In the present study, the term "caregivers" typically refers to paid persons at a residential care facility who assist women with intellectual disability with activities of daily living.

Intellectual disability

Intellectual disability is an evolving concept which acknowledges that disability results from the interaction between a person with an impairment/s and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others (United Nations, 2006). As such, it reflects "the fit" between the capabilities of the individual and the structure and expectations of the environment (Bornman & Rose, 2010). In the current study, the focus is on adult women above the age of 18 years, characterised by sub-average functioning, which limits two or more adaptive skill areas, namely communication skills, health and safety skills, functional academics, leisure or work. In this thesis, the classifications based on ability level (or IQ-scores) are not used as the emphasis is on the amount of support required by the individual. IQ tests are often not a true reflection of abilities and hence, this thesis moves away from the medical classification (where the emphasis is on the individual and the "problem") to a more functional classification, where the emphasis is on the effect of the impairment and the role of the environment. This also reflects the World Health Organisation's classification system, the ICF (International Classification of Functioning Disability and Health) (WHO, 2001), which emphasises opportunities and barriers the individual faces in everyday participation in his or her specific environment.

Knowledge

Knowledge refers to the body of information possessed by a person, or by a group of persons or a culture. Knowledge by results is a general term used to provide feedback to an individual in a learning situation about success or failure in mastering material (Russell, 1926). In other words, knowledge refers to the cognitive domain of learning and is associated with an understanding of and a reproduction of facts (Bradshaw, 1989). In this study the focus will be on knowledge regarding various aspects related to sexuality specifically.

Residential care facility

In the South African context, a residential care facility is mostly self-identified by its residents. For example, it provides special care to youths and adults with various types of disabilities. In their descriptive study aimed at describing residential care facilities in South Africa, McKenzie, McConkey and Adnams (2013) reported that two thirds of residential care facilities are situated in urban areas and the majority of residential care facilities were established with a median operating of 20 years. Furthermore, descriptive research results show that more women than men live in such facilities, that the highest proportion of residents are aged between 36 and 59 years, and that the residents are rated as having severe and multiple disabilities compared to individuals with moderate and mild levels of disability, who were more likely residing in group homes.

Sexuality

The WHO (2000) defines sexuality as "a core dimension of being which includes gender, sexual and gender, gender identity, sexual orientation, eroticism, emotional attachment/love, reproduction is experienced or it is expressed in thoughts, fantasies, desires, beliefs, attitudes, values, activities, practices, roles and relationships. Sexuality is therefore a result of the interplay of biological, psychological, socio-economic, cultural, ethical and religious factors" (Talbot, Astbury, & Mason, 2010, p.231).

Sexuality is also closely related to the concept of sexual health, which may be defined as the experience of the on-going process of physical, psychological and social-cultural well-being related to sexuality (WHO, 2000). Sexual health is not the absence of dysfunction or disease, but also encompasses the capacity to enjoy and control sexual behaviour with social and personal ethics, freedom from fear, shame, guilt and

other psychological factors which may inhibit sexual response and diseases which interfere with their sexual lives and reproductive choices (Talbot, Asbury & Mason, 2010; WHO, 1975).

1.5 LIST OF ABBREVIATIONS

ASD:	Autism Spectrum Disorder.
aSeRT:	a Sexuality and Relationship Training programme.
ASQ – ID:	Attitudes to Sexuality Questionnaire for Individuals with an Intellectual Disability (Cuskelly & Gilmore, 2007).
CRPD:	Convention on the Rights of Persons with Disabilities (United Nations, 2006).
DDSAS:	Developmental Disabilities Sexuality Attitudes Scale (Jorrisen, 2008).
EBP:	Evidence-based practice.
GSAQ-LD:	Greek Sexuality Attitudes Questionnaire – Learning Disabilities (Karellou, 2003).
HIV/AIDS:	Human immunodeficiency virus infection and acquired immune deficiency syndrome (Karellou, 2007).
HPCSA:	Health Professions Council of South Africa (HPCSA, 1974).
ICF:	International Classification of Functioning, Disability and Health (WHO, 2001).
IQ:	Intelligence Quotient.
NoSSA II:	Nottingham Study of Sexuality and Aging (Bouman, Arcelus & Benbow, 2007).
POS:	Perceptions of Sexuality Scale (Scotti, Slack, Bowman & Morris, 1996).
SA:	South Africa.
SexKen-ID:	Sexuality Knowledge Experience Feelings and Needs Scale – Intellectual Disability (Szollos & McCabe, 1995).
SIDAI:	Sexuality and Intellectual Disabilities Attitudes Inventory (Murray, MacDonald, Brown, Levenson, 1999).

- SMRAI:** Sexuality and Mental Retardation Attitudes Inventory (Brantlinger, 1983).
- UN:** United Nations.
- WCFID:** Western Cape Forum for Intellectual Disability (Johns, 2005).
- WHO:** World Health Organisation.
- WISC-IV:** Wechsler Intelligence Scale for Children – Fourth Edition (Wechsler, 2003).

1.6 SUMMARY

This chapter provided the motivation for the study by describing the background information that led to the development of the research through highlighting its relevance and contribution. It also provided an outline of the different chapters, through which the aims of the study will be realised. It concluded by providing a list of terminology clarification and abbreviations.

CHAPTER 2

Literature Review

2.1 INTRODUCTION

In Chapter 2, the social systems theory of sexuality of sexuality is proposed. This chapter starts by acknowledging the sexuality and sexual identity of women with intellectual disability. Thereafter, their sexuality needs and various misconceptions and myths are addressed. This is followed by a brief discussion of three disability models, namely the psychological model, the medical model and the social model. The chapter concludes by describing the various components of the proposed social systems theory, namely the primary stakeholders (women with intellectual disabilities and their right to sexuality education and sexual identity), the policy system, the secondary stakeholder group (the caregivers at the residential care facilities), the pedagogical system, and finally, the development of the sexuality training programme. The essence of this literature survey is presented in Figure 2.1.

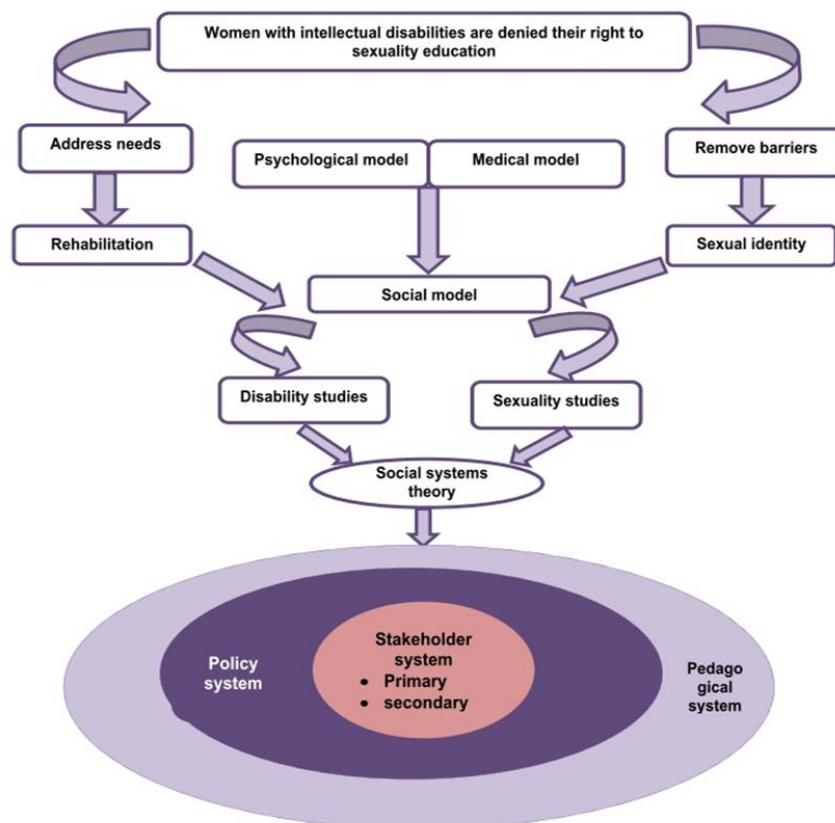


Figure 2.1 Social systems theory approach to sexuality using a Venn diagram

2.2 SEXUALITY OF WOMEN WITH INTELLECTUAL DISABILITIES

Sexuality is a multi-faceted construct (Cuskelly & Gilmore, 2007). Sexuality knowledge is more than just the sum of facts about body parts and sexual behaviour (Forchuk, Martin & Griffiths, 1995; Medlar, 1998; Sweeney, 2007). For women, sexuality embraces the life experiences of touch, affection, intimacy, self-worth, dignity and competence in regard to their interpersonal relationships (Medlar, 1998). Therefore, sexuality is the one way in which women define themselves as it is an extension of our self-esteem and can influence our interaction with others. The quality of and competence within interpersonal relationships are determined by how good women feel about themselves: being worthy of receiving and the capability of embracing life experiences (Matich-Maroney, Boyle, & Crocker, 2003; Medlar 1998).

Sexuality is one of the important elements that form women with intellectual disabilities' identity. Sexuality is expressed by a woman in many ways: the way she dresses, if she wears make-up, if she flirts with someone, how confident she is in life and the relationships she forms. Being able to express one's sexuality is just one part of the overall communication of the self – albeit an important part of life and how one's identity is expressed. For women with intellectual disability the constant denial of the expression of sexuality has a detrimental effect on their confidence and self-worth (Bonnie, 2004). There exists a dearth of literature on how women with intellectual disabilities develop their sexual identity or conceptualise their own identity (Fitzgerald & Withers, 2011). In some cultures, it is as if women with intellectual disabilities are viewed without gender and sexuality, with their only needs and desires in relation to their intellectual disability. However, there is coherent literature around how individuals who do not have an intellectual disability develop a sexual identity. Recent bio-psycho social models incorporated the influence of factors of the individual's micro-social context, culture and religious influences into the development of sexuality (Fitzgerald & Withers, 2011). When applying these models to the sexual identity development of women with intellectual disabilities they would predict negative sexual identities if taking into account negative attitudes that exist towards the sexuality of women with intellectual disabilities both in the micro-social contexts and in the wider culture (Fitzgerald & Withers, 2011).

Milligan and Nuefeldt (2001) notes that individuals with intellectual disabilities are often viewed as lacking the capacity to appropriately express their sexuality needs. Women with intellectual disabilities' lack of sexuality knowledge limits their ability to recognise potential sexual abuse and exploitation (Forchuk, et al.,

1995). In addition, their social incompetence prevents them from being involved in positive intimate relationships (Forchuk et al., 1995). Wilkerson (2002) highlights the fact that women with intellectual disabilities have to contend with social and cultural denial of their sexuality to illustrate the challenges surrounding them. Furthermore, women with intellectual disabilities are seldom portrayed in a positive light in the media, movies or television and advertising industries, but rather as the recipients of charity, evil characters in movies or the tragic victims of illness or accidents (Bonnie, 2004). They are also rarely portrayed as being involved in relationships but rather perceived as an unspoken taboo excluded from any discussion or representation by society, which reinforces the notion of the asexuality of women with intellectual disability (Bonnie, 2004).

In order to address the unspoken taboos and myths around sexuality two simultaneous activities are required: addressing the need specifically and addressing misconceptions to illustrate the challenges surrounding sexuality in women with intellectual disability. One of the reasons why women with intellectual disabilities find it difficult to learn about their own sexuality is because the training methods which are used to address the complex and emotionally laden construct of their own sexuality knowledge are ineffective. Research indicates that within the disability field, women with intellectual disabilities are the silent voices in the knowledge of their sexuality (Grieveo, McLaren, Lindsay & Culling, 2008; Hanna & Rogovsky, 1991; Talbot & Langdon, 2006).

2.3 ADDRESSING SEXUALITY NEEDS

According to Fitzgerald and Withers (2011), there is a need to focus on the sexuality of women with intellectual disability from a sexual abuse perspective. Current research needs to focus on sexuality education, the thoughts and feelings of women with intellectual disabilities related to their sexuality and sexual identity. These women struggle to develop positive sexual identities. Reason being the cumulative effects of negative social attitudes to the sexuality of women with intellectual disabilities as well as restrictive social perspectives on the sexuality of women in general (Fitzgerald & Withers, 2011). Negative attitudes to the sexuality of women with intellectual disabilities result in the sexual needs of these women frequently being ignored, curtailed or actively being denied by professionals as well as the general community (Morales, Lopez & Mullet, 2011; Szollos & McCabe, 1998). Protective attitudes toward women with intellectual disabilities are generally motivated by the desire to protect them from unpleasant

experiences, although it is these very experiences which help them grow (Deeley, 2002). Attention needs to be paid to what women with intellectual disabilities want in terms of support on sexuality education, asking caregivers for their perspectives on what they think would give a clear indication of what sexuality and relationship training education programme should address. Therefore, for example, when asking 21 young women with intellectual disabilities about sexuality they stated that their main interests were related to friendship and dating (Bleazard, 2010). Finding the means to empower women with intellectual disabilities to acknowledge, welcome and take control of their own sexuality should be seen as a high priority within an established continuous sexuality and relationship training education programme with a residential care facility.

2.4 ADDRESSING MISCONCEPTIONS

While the needs of women with intellectual disabilities should be addressed, misconceptions should simultaneously be addressed, as these aspects are two sides of the same coin.

Myth one is the belief that the biological defects that exists in women with intellectual disabilities render them unable to have feelings of a sexual nature. The second myth is that if sexual functioning is possible, women with intellectual disabilities have limited social judgment, lacking the capacity to engage in responsible intimate relationships. In addition, women with intellectual disabilities are viewed as not having the cognitive skills to think abstractly as would typically developing adults, questioning whether they will be able to follow social norms and societal expectations surrounding socially appropriate behaviour (De Loach, 1994). In their study on attitudes and perceptions towards disability, Esmail, Darry, Walter and Knupp, (2010, p 1151) found that some individuals with disability were taught that sexuality was not equivalent to their typical peers and that they should only “be with other people with disability”. Aunos and Feldman (2002, p 287) also reported that ten out of 13 persons with disability stated that sexuality was a “dirty and nasty business” and apart from that, they were generally not knowledgeable concerning sexuality topics. Moving from large institutional settings into residential care facilities, the community attempted to lessen the perceived risk of sexually deviant behaviour by attempting to eradicate sex drives through medication (Bernstein, 1985).

The Western Cape Forum for Intellectual Disability (WCFID) in South Africa reported a range of different

perceptions regarding sexuality of people with disability, which reflect these misconceptions (Johns, 2005). Firstly, society often refuses to accept the sexuality of women with intellectual disabilities (Johns, 2005). Secondly, the literature portrays women with intellectual disabilities in a negative position related to their own sexuality by labelling them as vulnerable, a high-risk population and perpetual children (Swango-Wilson, 2008). Thirdly, society perceives women with intellectual disabilities as being "sexually innocent", still needing protection from sexual experiences (Bryen, 2014; Johns, 2005). Fourthly, women with intellectual disabilities are also viewed as "promiscuous" and incapable of dealing with sex responsibly (Christian, Stinson & Dotson, 2001; Cuskelly & Bryde, 2007; Karellou, 2003; Szollos & McCabe, 1995).

All of these misconceptions contribute to the fact that out-of-school females are the most vulnerable group at risk of sexual abuse (Christian et al., 2001; Cuskelly & Bryde, 2007; Karellou, 2003; Szollos & McCabe, 1995). With limited educational opportunities to learn about their own sexuality, women with intellectual disabilities are often denied the right to make choices to engage in appropriate intimate relationships (McCabe, 1999; Phasha, 2009; Swango-Wilson, 2009). This could predispose them to sexual abuse (Bryen, 2014). Adding to this dilemma is that parents avoid addressing sex education with their intellectually disabled daughters (Aunos & Feldman, 2002). Firstly, parents do not know how to approach sexuality matters. Secondly, parents fear that it will encourage and add to the stigma that filling the gap in the sexuality knowledge of their children with intellectual disabilities will result in an increase in sexual activity (Grieveo, Lindsay & McLaren, 2006; Isler, Beytut, Tas & Conk, 2009).

One of the reasons why women with intellectual disabilities find it difficult to learn about their own sexuality is due to the training methods used to address the complex and emotionally laden construct of their own sexuality knowledge. Research indicates that within the disability field, women with intellectual disabilities are the silent voices in the knowledge of their sexuality (Hanna & Rogovsky, 1991).

For women with intellectual disability, the constant denial of the expression of sexuality has a detrimental effect on their confidence and self-worth (Bonnie, 2004). There exists a dearth of literature on how women with intellectual disabilities develop their sexual identity or conceptualise their own identity (Fitzgerald & Withers, 2011). In some cultures it is as if women with intellectual disabilities are viewed without gender and sexuality, with their only needs and desires being in relation to their intellectual disability. This denial of sexual identity in women with intellectual disabilities results in there being limited or no coherent literature

available on how they conceptualise their sexuality or develop a sexual identity (Fitzgerald & Withers, 2011). However, there is coherent literature around how individuals who do not have an intellectual disability develop a sexual identity. Recent bio-psychosocial models have incorporated the influence of factors of the individual's micro-social context, culture and religious influences into the development of sexuality (Fitzgerald & Withers, 2011). When applying these models to the sexual identity development of women with intellectual disabilities they would predict negative sexual identities, if taking into account the negative attitudes that exist towards the sexuality of women with intellectual disabilities both in the micro-social contexts and in the wider culture (Fitzgerald & Withers, 2011).

2.5 DISABILITY MODELS

Three disability models are discussed specifically regarding their relevance to sexuality, namely the psychological model, medical model and social model.

2.5.1 Psychological Model

The existing psychological models of disability pay little attention to the impact of sexuality and sexual identity development on an individual's experience with disability. There have been some attempts in psychology to address the intersections of disability and sexuality (Schulz, 2009). When sexuality is described in connection with disability, the disability is often viewed as being "superimposed" upon otherwise healthy sexual functioning (Schulz, 2009). Although the research in this area is extremely limited, various researchers and clinicians have attempted to propose models that accurately reflect the psychological impact of disability on sexuality (Schulz, 2009). The literature on the impact of disability on sexuality struggles to account for the sexual expressions of individuals with intellectual disabilities in terms of desire, arousal and positive sexual functioning. For example, a psychological model was proposed to develop valid and reliable measurements of physical disability on sexual activity and satisfaction (Schulz, 2009).

2.5.2 Medical Model

This particular model focuses on the individual with the disability and, in particular, physical defects

(Parchomiuk, 2012). The defects that led to the limitations in functioning were treated as the basis of the disability. From the perspective of the individual, disability was assumed to be the source of a personal tragedy. Professional activities, mostly of a medical nature, focused on adjusting to the state of limited functioning seen in a reductionist way – as accepting the loss (of ability or independence). The key aspect of the individual (medical) model is its reduction or ignorance of the significance of the individual's activity in the process of coping with the effects of disability, as well as neglecting personal experience. Hence, this model is limited, and to a certain extent, deterministic, in perceiving the essence of disability (Parchomiuk, 2012). The medical model alongside the basic concept of impairment treats the sexuality of individuals with disabilities in categories of a medical problem. Impairments of bodily structures and functions expected to lead the inability to satisfy one's own sexual needs are one of the elements of experiencing the personal tragedy (Parchomiuk, 2012). In treating sexuality, the dominant tendency is biologics and medicalisation of professional activities. The medical approach to sexuality perceives its essence in the ability to engage in sexual intercourse. An inability to take part in it, due to physical limitations, leads to a false generalisation regarding the lack of sexual needs of individuals with a disability (specialists focus mainly on individuals with a physical disability) (Chivers & Mathieson, 2000). The sexuality of individuals with intellectual disability is not evaluated as positive, even from a physical perspective. It is not considered an element of their personal tragedy or an object of activity aimed at reaching an adjustment to the disability – as opposed to the case of individuals with a physical disability (Parchomiuk, 2012).

2.5.3 Social Model

The social model of disabled sexuality offers a fundamental and vitally important critique of assumptions concerning individual's sexuality (Rembis, 2010). Rembis (2010, p. 53) describes disability sexuality studies as "the institutionalization of disability studies and the proliferation of a vibrant and dynamic culture, both of which have their roots in disabled activism and the social model of disability, giving rise to a whole new sub-field". In the 1980s, feminist disability scholars and those researchers and activists committed to a social model of disability began to deconstruct dominant assumptions concerning disabled sexuality (Asch & Fine, 1988; Hahn, 1981; Thomson, 1997). Still acknowledging the embodiment of disability, the feminist disability scholars, researchers and activists began to highlight and specialists to become an object of reflection concerning personal experiences (Rembis, 2010). Hence, this model illustrates that the sexuality of individuals with disabilities is to be viewed from a broad perspective that considers the essence of

disability itself.

2.6 DISABILITY AND SEXUALITY STUDIES

There are a variety of issues on disability and sexuality that characterise women with intellectual disabilities as either being asexual or sexually deviant (Jorisson & Burkholder, 2013). Eugenics (Richardson, 2005) is acceptable and at times preferred as a way to control sexuality, inappropriate sexual behaviours and the reproduction of individuals with intellectual disabilities (Richardson, 2005). In the past it was seen as unnecessary and possibly even as unwanted to provide women with intellectual disabilities with the information to protect themselves against sexual abuse and exploitation, as it was generally accepted by society that women with intellectual disabilities are different in the development of their sexuality. The views of society are frequently polarised into the position that women with intellectual disabilities should be discouraged from engaging in such behaviour. The belief systems about the sexuality of women with intellectual disabilities are developed into societal myths and misperceptions, as described earlier. These, in turn, result in myths and misconceptions and a history of oppression of women with intellectual disabilities' acknowledgement of their sexuality and the education thereof (Jorisson & Burkholder, 2013). Moving from large institutional settings into residential care facilities, the community attempted to lessen the perceived risk of sexually deviant behaviour by attempting to eradicate sex drives through medication (Bernstein, 1985).

2.7 SOCIAL SYSTEMS THEORY

Three critical systems should be considered in the development of training programmes, namely the Policy system, the Stakeholder system (including both the primary and secondary stakeholders) and the Pedagogical system.

2.7.1 Policy System

Concerns of staff, caregivers and parents for the sexual health of the women with intellectual disabilities encourage these parties to implement protective policies. It is pragmatic for those charged with the care of these women to have certain unease about the women's capabilities for healthy sexuality and social expression when attenuated cognitive functioning and deficits in adaptive behaviours influence the women's basic functioning (Bernert, 2011). Protective policies are attempts to mediate the dilemmas professionals and caregivers experience when balancing the social and sexuality integration of women with intellectual disabilities with safety and support services (Bernert, 2011). These policies can be protective agendas for residential care facilities. "I think places are so afraid that if 'something happens' while they are on duty that they will get reported" (Bernert, 2011, p 138). The policies that serve to protect the women with intellectual disabilities from sexual vulnerability and other risks are not without risks to these women. However, Bernert (2011, p 134) states in his focus group, several reasons why women with intellectual disabilities might employ protective behaviours, including "an attitude between staff and the women with intellectual disabilities". Maybe it is the way that [staff] talk to them, instead of communicating like they should, which demonstrates the attitudinal problems of the staff. Another woman observed "some don't like other people tellin' them what to do" (Bernert, 2011, p 134). [Staff] set the rules that women have to follow, where they live, for example, when to bath, when to go to sleep, when to watch TV, when to eat, etcetera. One of the participants who participated in Bernert's (2011) study also mentioned that women with intellectual disabilities who get supervised all the time "get frustrated and mad" because they cannot come and go as they desire (Bernert, 2011, p 134). Being in control seemed an accurate assessment of the protective behaviours among women and that "something" appeared to be their sexuality.

2.7.2 Stakeholder System

i) Primary stakeholders: Right to sexuality education

The NHS Westminster Policy (2003) state that human rights are an ethical ideal; a way of reaching across the divisions of country, ethnicity, gender, class and conduct in search of what is common to all individuals across the world. Human rights lay down the minimal conditions required to lead worthwhile lives. At the heart of a worthwhile life resides individual judgments and the pursuit of personal goals. It is agency that bestows dignity on human beings - the fact that individuals are able to translate their ideals and dreams into

effective action gives their lives shape and meaning (NHS Westminster, 2003). The United Nations confirms in the Declaration on the Rights of Mentally Retarded Persons (UN, 1983, p.141), that individuals with intellectual disabilities have a right "to sex education training, rehabilitation and guidance that will enable [them] to develop [their] disabilities to their maximum potential".

ii) Secondary stakeholders: Caregivers at residential care system

Caregivers are important to the social experiences and sexual identity formed by women with moderate intellectual disabilities (Swango-Wilson, 2008). Furthermore, caregivers often contribute the importance of sexuality experiences to the development of social skills. However, they rarely report leaving women with intellectual disabilities alone to explore and develop their own sexual identities in a social situation (Swango-Wilson, 2008). This inability of women with intellectual disabilities to explore their own sexuality in social settings tends to limit them in their development of friendships and other interpersonal relationships outside their immediate environment. The ability to develop social decision-making skills related to good and bad relationships is also influenced by the limited exposure to social situations (Halstead, 2002). Caregivers are important to the development of social skills that will allow for community integration (Swango-Wilson, 2008). In addition, caregivers provide the social experiences that allow women with intellectual disabilities to define their personal space boundaries and the recognition of appropriate and inappropriate behaviours that violate that space boundary (McCabe, 1998; McCabe, 1999; McConkey & Ryan, 2001). Caregivers' attitudes are important to the educational experience and the development of social skills of women with intellectual disabilities living in residential care (Jorriesson, 2008; Swango-Wilson, 2008). Gilmore and Chambers (2010) found that with appropriate training, disability support staff (such as caregivers) generally held positive attitudes towards the sexuality of individuals with intellectual disability. In addition, the beliefs and attitudes of these caregivers related to the sexuality of these women are exerted towards the development of their sexual identity (Swango-Wilson, 2010). To strengthen women with intellectual disabilities' resources within education, they need to be empowered with the tools needed to integrate into society successfully (McConkey & Ryan, 2001). Therefore, caregivers' play an important role in the lives of women with intellectual disabilities on aiding the development and integration of appropriate personal space and the recognition of appropriate and inappropriate behaviours in both public and private places that cross personal boundaries of others within their space (Swango-Wilson, 2008). By embracing the social systems theory, women with moderate intellectual disabilities' quality of life within residential care facilities will be enhanced, as will the quality of their interpersonal relationship skills on all levels. In

addition, their vulnerability to sexual abuse and exploitation will decrease simultaneously (Swango-Wilson, 2010).

2.7.3 Pedagogical System

To illustrate the challenges surrounding the low levels of sexuality knowledge in women with intellectual disabilities, Lockhart, Guerin, Shanahan and Coyle (2010) highlight the following: (i) the difficulties women with intellectual disabilities experience with the learning and retention of information; (ii) the inadequate provision of sexuality education to these women and; (iii) their inadequacy to maintain healthy intimate relationships. Researchers have attempted to design and implement sexuality training programmes that serve to address these challenges and act as cornerstones to promote and increase sexuality knowledge with the aim to evaluate the effectiveness of the programmes as intervention tools, but with limited success (Grieveo et al., 2008; Lindsay, 2002; Talbot & Langdon, 2006). Gougeon, (2009) argues that current educational practices fail to address the sexuality needs of women with intellectual disabilities. As a result, their full citizenship is denied (Morales, Lopez, & Mullet, 2011). Furthermore, Gougeon (2009, p 277) continues to address the current practices that fail to teach the “ignored curriculum of sexuality” to women with intellectual disabilities. This “ignored curriculum of sexuality” is the incidentally learned aspects of sexuality by typically developing adult women usually through interactions with others. As discussed earlier, current sexuality education for women with intellectual disability is portrayed within a historical treatment of media portrayals, how society negates these women with intellectual disabilities’ identities in their current form, promoting their incompetent sexuality knowledge, resulting in social exclusion, having legal implications and ultimately having denial of their identities as sexual beings in the community which these women are being kept apart from peers without disability (Gougeon, 2009). Therefore, the existing problem is the lack of meaningful and comprehensive sexuality education within residential care facilities for women with intellectual disabilities. While the vast majority of publications regarding sexuality addresses education for all individuals with disabilities, the form and content of such education supports the claim that the sexuality education remains an issue of contention for many (Boehning, 2006; Constantine, Slater & Carroll, 2007; Spiecker & Steutel, 2002). It is unfortunate that women with intellectual disabilities are frequently excluded completely from the realm of sexuality education. Hence, when they are included, it is most often reactive rather than proactive, commonly addressed only after women with intellectual disabilities have become sexually active (Boehning, 2006; Gerhardt, 2006). Adopting a reactive approach

rather than a proactive one increases the likelihood of women with intellectual disabilities staying uninformed or being misinformed comprising them of self-advocacy skills. This increases their risk of being sexually abused and exploited and contracting a sexually transmitted disease. Inappropriate socio-sexual behaviours occur more frequently as a result of social exclusion and isolation. The “ignored sexuality education curriculum” is unacknowledged and untaught by many caregivers within residential care facilities, resulting in these skills being learned incidentally by the women with intellectual disabilities, typically through interactions with peers. The “ignored sexuality education curriculum” is learned during typical conversations incidentally between peer interactions from which women with intellectual disabilities are often precluded. Unfortunately this “ignored sexuality education curriculum” is primarily unavailable to women with intellectual disabilities. Reasons being that they are constantly under adult surveillance, which negatively impacts their ability to build and foster relationships with their non-disabled peers (Gougeon, 2009). In addition, these women are often in segregated residential facilities where they have no opportunities of interacting with non-disabled peers. Being in an inclusive setting, most times, the caregiver acts as their mediator. With constant adult presence, women with intellectual disabilities are unable to have meaningful exchanges with typical peers, since the typically adult presence negates the possibility of the ignored curriculum to occur. Furthermore, women with intellectual disabilities are less likely to participate in extra-curricular activities and are not often employed part-time, two prime areas that exclude them from peer interaction and social integration which could act as a source of sexuality instruction. Appendix A shows an alphabetical literature review related to published sexuality education studies for individuals with intellectual disabilities.

2.8 DEVELOPMENT OF SEXUALITY TRAINING PROGRAMME

One of the reasons why women with intellectual disabilities find it difficult to learn about their own sexuality is the training methods used to address the complex and emotionally laden construct of their own sexuality knowledge. Attempts by numerous researchers have been made to develop and implement training programmes to explore the sexuality knowledge of individuals with intellectual disabilities (Grieveo, et al., 2006).

Table 2.1: Sexuality training programmes

Name of programme	Living safer sexual lives (Frawley et al., 2003)	Step-by-step (Johns, 2005)	Relationships and sexuality project (Gardiner & Braddon, 2009)
Aim of programme	What people with learning disabilities see as important about sexuality and relationships; how sexuality and relationships fit into the lives of people with learning disabilities; develop and try ways of helping people with learning disabilities lead safer sexual lives, using people's stories.	Give practical guidance programme to assist staff, parents and educators to provide sexuality and HIV/AIDS education to individuals with intellectual disability.	Sex education will lead to safer and more fulfilling sexual lives to people with intellectual disabilities.
Target population	25 individuals with learning disabilities between 25 and 60 years old: 12 men and 13 women.	Young adults with mild to moderate intellectual disability.	Adults with intellectual disabilities and mixed abilities.
Method used	Stage 1: Collection of 25 stories from individuals with learning disabilities Stage 2: Use of stories to develop workshops and resources on sexuality and relationships of individuals with learning disabilities, families and service providers.	Session-by-session outlined in the format of a pilot programme; A video to supplement and assist facilitator in becoming more familiar with the activities of the group (available in Afrikaans and isiXhosa).	A multi-disciplinary group was identified that employed an independent trainer to develop a training programme specific to the needs of the group; 15 multi-disciplinary staff delivered the programme to two pilot sites in a rural area.
Advantages	Service providers stated that the use of stories are effective in breaking down barriers; Individuals with learning disabilities could identify with the social stories; Parents commented that they had time to assess their own beliefs of what they thought their son's rights were (Frawley, Johnson, Hillier & Harrison, 2001).	At the end of each session, lessons and feedback from the programme was provided applicable to the SA context and translated into two indigenous languages.	The effect of the programme was difficult to assess: improvements were reported in self-esteem and levels of education in sexuality and relationships for some.
Disadvantages	Possible trigger for disclosure of sexual abuse that could cause trauma.	The effectiveness of the programme was not measured.	Limited improvements were reported in terms of social inclusion and participation in everyday life because of social isolation living in a rural area, lack of transport limiting taking part in social activities. Parents had no input into the content of the programme.

Table 2.1 shows the three different training programmes on sexuality knowledge that were found. The importance of sexuality education is highlighted by all the programmes for the same target population, namely individuals with intellectual disabilities. Though all the programmes have similar aims, the effectiveness of these programmes has yet to be measured. None of these programmes used social stories to explain socially appropriate behaviours.

2.9 SUMMARY

This chapter provided the literature review used in the study. It argued for the use of a social systems theory approach to sexuality which incorporates both primary stakeholders (women with intellectual disabilities) and secondary stakeholders (caregivers at the residential care facilities) as well as the policy and pedagogical systems. Chapter 2 also briefly alluded to three different disability models that should be considered. It also underscored the sexuality needs of women with intellectual disability and described the most common myths and misconceptions held by society regarding their sexuality.

CHAPTER 3

Phase 1: Qualitative data

3.1 INTRODUCTION

Chapter 3 describes the planning and development of a sexuality and relationship training programme. It is based on social systems theory discussed in Chapter 2, which acknowledges the importance of basing it within a policy system, a stakeholder system and a pedagogical system. The programme was designed to encourage, facilitate and support caregivers within residential care facilities, who work with women with intellectual disabilities to view education and relationship building as an integral part of these women's lives.

This study used a three-phase research design. Phase 1 focused on the qualitative data and how this informed the design considerations of the training programme. Phase 2 focused on the development of the training programme, and Phase 3 on the quantitative data and the main study. Figure 3.1 shows the outline of all three phases, specifically highlighting Phase 1, as this is the focus of the current chapter.

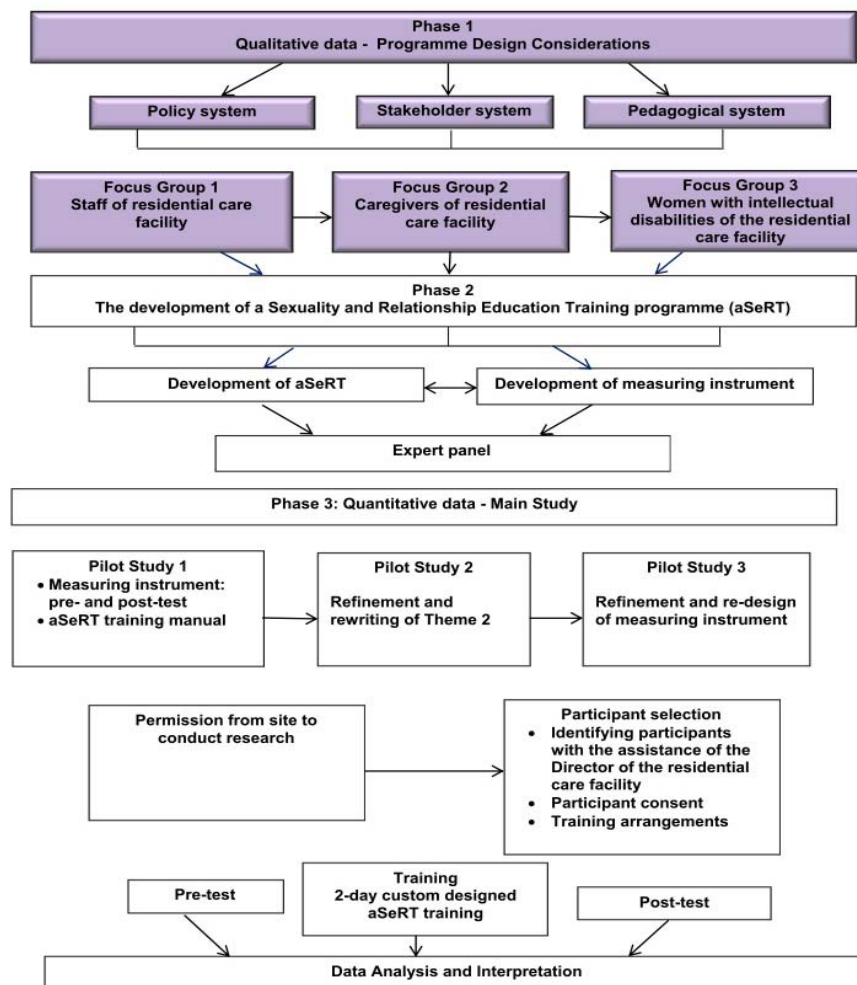


Figure 3.1: Schematic outline of the three research phases: Phase 1

3.2 POLICY SYSTEM

The Convention of the Rights of Persons with Disability (United Nations (UN) General Assembly 2006) a human rights instrument, confirms that state parties should take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others. Historically, in South Africa there has always been tension between a human rights discourse and a discourse on restriction of behaviours related to sexuality of individuals with intellectual disability (Rohleder, Swartz, Eide & McGregor, 2009). However, South Africa's Mental Health Care Act 17 of 2002 stipulates in section 2 "every organ of State responsible for health services must determine and coordinate the implementation of its policies and measures in a manner that (a) ensures provision of mental health care, treatment and rehabilitation services at primary, secondary and tertiary levels..." (Republic of South Africa, 2002, p.10).

It is important for an adult residential care facility to have an established sexuality policy in place and for responsibilities to be clear. Issues of confidentiality and disclosure during the sexuality and relationship education training programme should be established beforehand. In addition, reference should be made to other relevant policies, as members of the staff need to feel empowered, equipped and supported to understand these policies and their implementation implications, as well as the demands this would place on them. A sexuality policy within a residential care facility has to be relevant to the needs of all involved, including the women with intellectual disabilities, staff at the facility and all other relevant service providers and policy makers (Cambridge & McCarthy, 1997).

One of the main reasons why sexuality education is formalised through policy systems and guidelines is that service providers for women with intellectual disabilities find sexuality a difficult and contentious issue to address (Cambridge & McCarthy, 1997). However, the successful implementation of a sexuality policy within adult residential care facilities for this population cannot be accomplished without the full cooperation of the staff and all the stakeholders discussed earlier (Grieveo, McClaren, Lindsay & Culling, 2008; Trudel & Desjardins, 1992). In fact, the Mental Health Care Act 17 of 2002, section 4, is explicit about this, and clearly states that "all service providers for health services should be involved in determining and coordinating the implementation of the relevant state policies to ensure that, among other things, the rights and interests of mental health care users are promoted and that mental health status is thereby improved" (Republic of South Africa, 2002, p.10). Furthermore, such a policy needs to consider caregivers' attitudes toward the sexuality of women with intellectual disabilities to ensure that they understand sexuality as part of a human-rights paradigm. Hence, caregivers should be actively involved and consciously aware that interpersonal relations between residents under certain

circumstances, supported by a sound sexuality policy, have a beneficial effect (Trudel & Desjardins, 1992). According to the Mental Health Care Act 17 of 2002 section 14 (Republic of South Africa, 2002, p 13), "subject to conditions applicable to providing care and rehabilitations services in health establishments, the head of a health establishment may limit intimate relationships of adult mental health care users only if due to mental illness, the ability of the user to consent is diminished". Cambridge and McCarthy (1997) state that the continued economic and social marginalisation of women with intellectual disabilities, which is reinforced by segregation and social exclusion, often results in these women having to depend and rely on service providers for their needs and wants, and become barriers that act as disincentives to sexuality education and relationship building in their everyday lives.

In addition, women with intellectual disabilities are likely to be vulnerable within segregated environments, such as residential care facilities. In these facilities, service providers often tend to view sexuality as a problem that needs to be "managed" (Esmail, Darry, Walter & Knupp, 2010). However, a more sustainable long-term alternative could be the empowerment of these women with intellectual disabilities through the necessary education programmes that would allow them to participate more actively in the community, and to make more informed and safe choices related to their own lives, including sexuality (Cambridge & McCarthy, 1992). By excluding these women from active decision-making and leaving them powerless, their vulnerability is increased, therefore perpetuating and possibly even increasing potential sexual exploitation (Bryen, 2014).

In conclusion, if the policy is to have relevance to the lives and experiences of the women with intellectual disabilities, their interests need to be formally acknowledged and represented in the policy development process, simultaneously with a sexuality training programme (NHS Westminster, 2003).

For each of the four aspects related to the policy, the policy will first be described, followed by a discussion of the relevant guidelines.

3.2.1 Sexuality and Relationship Education

i) Policy

A sexuality and relationship education programme should be developed and offered to all women with intellectual disabilities in order to enhance their understanding and skills in interpersonal relationships and to encourage safer relationships, including sexual relationships (NHS Westminster, 2003). The focus of the current research is on the first aspect that all staff, in the residential care setting, who work

with the women with intellectual disabilities, should be actively involved in the development of the sexuality and relationship education programme to encourage ownership of the programme and familiarity with its contents. Earlier studies have shown that staff at caregiving facilities are open to discussing sexuality and relationships with the individuals in their care, if they feel that they have received adequate training (Evans, McGuire, Healy & Carley, 2009; Healy, McGuire, Evans & Carley, 2009).

ii) Guidelines

Women with intellectual disabilities can acquire incorrect information and negative attitudes related to sexuality from different resources in their everyday lives, such as their peers, caregivers, television and/or other media sources, such as cell phones and technology. A formal programme on sexuality education and relationships can supplement, enhance and ensure that the correct information is taught to this vulnerable population. As far as possible, all service providers, such as residential care staff, should be encouraged to develop and implement a sexuality and relationship education programme for caregivers who work directly with women with intellectual disabilities. In doing so, these women will be less vulnerable to sexual exploitation and abuse and become empowered to make informed decisions and have a better understanding of their own boundaries, as well as the boundaries of others. Therefore, a consistency in approach and messages received from trainers who implement the sexuality and relationship education programme should be well established within the care facility, making all staff aware of the content and scope of the programme, as well as the language and terminology used. Staff from within the residential care setting should take responsibility for the planning and delivery of the programme and might opt to also include outside stakeholders with specialist expertise (NHS Westminster, 2003).

3.2.2 Staff Support and Training

i) Policy

It is the responsibility of the staff at the care facility at various levels (for example, caregivers) to ensure that the women with intellectual disabilities understand the various aspects related to sexuality and interpersonal relationships and that they are allowed to express their sexuality in an appropriate manner. In order to achieve this, staff need to be supported in all aspects of their work which concerns the sexuality of the women in their care, as their training is of key importance in implementing and monitoring the sexuality policy, as well as in the implementation of a sexuality and relationship training programme discussed earlier (NHS Westminster, 2003).

ii) Guidelines

All staff at residential care facilities need to be aware of the sexuality and interpersonal relationship needs of women with intellectual disabilities so that they can work sensitively and appropriately with these women to ensure that they feel comfortable with their own sexuality. Therefore, all staff should be provided with the necessary information about the sexuality and relationship education programme. Ideally, such a training programme would include that:

- all newly appointed staff undergo the sexuality and relationship training as a compulsory part of their work;
- all current staff receive up-to-date information in the form of at least one refresher course per year; and
- designated staff at the facility undergo training following their basic sexuality and relationship induction and refresher training programmes (NHS Westminster, 2003).

Induction programmes could include sexuality awareness training, thereby creating an opportunity to develop staff's own sexuality knowledge and self-image. This, in turn, would lead to staff having a positive approach to sexuality education and relationships in individuals with intellectual disabilities. Particular attention therefore needs to be given to comments made by caregivers regarding sexuality. In addition, an opportunity should be provided to all staff who work closely with the women with intellectual disabilities to discuss the messages they communicate to these women, both explicitly and implicitly. All staff members, especially caregivers, need to be sensitised to some of the negative attitudes and myths commonly held regarding sexuality and women with intellectual disabilities (Aunos & Feldman, 2002; Johns, 2005; Phasha, 2009). Continual supervision and ongoing support need to be available for caregivers regarding this aspect. Furthermore, caregivers have the right to expect the following from management:

- a clear and consistent approach to the sexuality of women with intellectual disabilities, stipulated as a policy;
- clarification about lines of responsibility and accountability; and
- protection from sexual abuse and exploitation (NHS Westminster, 2003).

3.2.3 Developing Tailor-Made Education Programmes

i) Policy

It is recommended that each residential care facility develop a custom-made sexuality and relationship policy based on the Mental Health Care Act 17 of 2002, section 4, (Republic of South Africa, 2002), and the United Convention on the Rights of Persons with Disabilities Article 23 (UN, 2006) of 2000. However, it is important to take cognisance of the fact that these tailor-made policies may at no time contradict any part of the South African Constitution and/other relevant national laws. All staff should be involved in this process, to a lesser or greater extent. Wherever possible, women with intellectual disabilities should also be involved in discussions about these guidelines (Bleazard, 2010; NHS Westminster, 2003).

ii) Guidelines

All residential care facilities that provide services to adults with intellectual disabilities need to consider developing a tailor-made policy on sexuality. This type of individualisation implies that the principles of these policies can be interpreted for each particular residential care facility and that the women with intellectual disabilities should be involved in reaching agreement about matters that apply to their own context. It is important to ensure that all caregivers are aware of this policy and accompanying guidelines. All staff in the residential care setting should at some stage participate in discussions about establishing specific guidelines. Research has clearly demonstrated that more involvement will result in better outcomes (Bazzo, Nota, Soresi, Ferrari, & Minnes, 2007, Bouman *et al.*, 2007; Siebelink, de Jong, Taal, & Roelvink, 2006). Caregiver roles in relation to sexuality and relationship education should be made clear so that lines of accountability are known by all (Image in Action and Family Planning Association, 2013). A six-stage process is suggested for developing tailor-made policy guidelines for residential care facilities. In the development of the sexuality and relationship education programme, for the current study the same six steps were followed, namely:

1. Conduct an initial meeting with all staff and provide an overview of the existing policies (if applicable), as well as the national laws previously mentioned.
2. Seek agreement for the policy development process and identify one or two priority areas. Identify one or two caregivers to work on the priority areas, as well as a senior staff member to collaborate with the group (Image in Action and Family Planning Association, 2013). Staff identified during Stage 1 will therefore use their own experience and expertise to suggest what should be included in the guidelines of the policy during Stage 2. Other staff and stakeholders may add relevant information. Consulting with the women with intellectual disabilities for their input and suggestions is also encouraged (NHS Westminster, 2003).

3. Collate the first draft of the policy by using more general policies as a baseline on which to elaborate further.
4. Present the draft policy to all staff members during a feedback meeting.
5. Finalise the draft policy.
6. Redraft the policy into an accessible format for the women with intellectual disabilities, for example by using easy English, to have a clear understanding of the guidelines of the policy and how it will affect them. Translating the policy into an accessible, understandable format for individuals with intellectual disabilities is seen as an essential part of policy development (NHS Westminster, 2013).

The policy written by NHS Westminster (2003) suggests that accepting and respecting the sexuality of women with intellectual disabilities should be core elements to be included in such a policy, as should respect for their culture and religion, and how these affect sexuality. Finally, these women should also be provided with advice and counselling within a primary health-care programme related to sexuality and relationships when needed.

3.3 STAKEHOLDER SYSTEM

Acknowledging the importance of sexuality education does not imply that it will be addressed, particularly when an appropriate programme is not available (Plaute, Westling & Cizek, 2002). Therefore, an appropriate sexuality and relationship training programme which can be used as the standard programme in adult residential care facilities in South Africa, from which the tailor-made adaptations can follow, was developed. The researcher had intended to use the six-step process described earlier, though this was not feasible as there were no existing policies at residential care facilities visited. Hence, the development of a policy was started by conducting three focus groups with (i) staff of the residential care facility; (ii) caregivers of the women with moderate intellectual disabilities; and (iii) the women with moderate intellectual disabilities themselves. The focus group concerned with the women with intellectual disabilities provided them with the opportunity to share their own knowledge of sexuality and relationships and to make their voices heard.

Focus groups were selected as the preferred method of gathering the information, as they can encourage open conversation about sensitive subjects such as sexuality, and facilitate the expression of ideas and experiences that might otherwise be left underdeveloped (Kitzinger, 1994). As such, they provide insight into the operation of social processes in the articulation of knowledge through examining what information is censored or muted within the group (Kitzinger, 1994). There is a sizeable body of

literature on the use of focus groups to gain access and insight into “sensitive topics”, such as the current focus of the research where participants may be more comfortable sharing their experiences among a group of people with similar concerns (Carey & Asbury, 2012; Kevern & Webb, 2001). Furthermore, allowing participants to voice their opinions and knowledge in this way is also effective in creating social change as they feel valued in the process (Jorisson, 2008). In the present research, the focus groups include semi-structured sessions in an informal setting moderated by the researcher and co-facilitator, who used general guideline questions (Carey & Asbury, 2012).

In social research, the definition of a focus group is linked to its purpose, generally centred on the desire to explore participants’ perceptions, attitudes or ideas about a given issue (Kevern & Webb, 2001), as well as the beliefs that underlie behaviour (Carey & Asbury, 2012). Furthermore, it yields information from multiple sources and contains rich contextual data (Krueger, 1988). By providing context and perspective, focus groups enable the researcher to understand the phenomena under investigation in a more holistic manner. In addition, the manner in which participants describe their experiences can provide unique information on how they give meaning to and organise their unique experiences. Each of the three focus groups will now be discussed according to the aim, the participants’ biographical information, the methods used, the results obtained and the implications for the development of the programme. Appendices B, C and D contain the data transcripts from the three focus groups.

3.3.1 Focus Group 1 with Staff of the Residential Care Facility

The aim of Focus Group 1 was to determine staff’s perceptions regarding the sexuality of adult women with intellectual disabilities at an adult residential care facility for individuals with multiple disabilities. In addition, the focus group sought to determine what the staff thought would be important to be included in a training programme. The biographic information of the staff who work with women with intellectual disabilities in the adult care facility on a daily basis and who participated in Focus Group 1 is presented in Table 3.1.

Table 3.1: Biographic information of staff in the residential care facility (N=10)

Category	P1.1	P1.2	P1.3	P1.4	P1.5	P1.6	P1.7	P1.8	P1.9	P1.10
Gender	F	F	F	F	F	F	F	F	F	M
Age	38 years	56 years	28 years	32 years	38 years	27 years	31 years	38 years	48 years	55 years
Home language	Afrikaans	Setswana	Sesotho	Afrikaans	English	Afrikaans	Setswana	Setswana	Setswana	Afrikaans
Job description at care facility	Financial Manager	Laundry Supervisor	Cleaner	Social Worker	Instructor at Therapy House	Personal Assistant to CEO	Instructor at Sewing Workshop	Instructor at Therapy House	Cleaner	Workshop Manager
Time worked at the facility	3 years 2 months	7 years 2 months	2 years 0 months	7 years 9 months	7 years 0 months	0 years 8 months	3 years 4 months	8 years 0 months	5 years 0 months	3 years 6 months
Disability experience	3 years 2 months	7 years 2 months	2 years 0 months	7 years 9 months	7 years 0 months	0 years 8 months	3 years 4 months	8 years 0 months	5 years 0 months	3 years 6 months
Highest qualification	Diploma (N5)	Gr 12	Gr 12	Bachelor's Degree	Gr 10	Gr 12	Gr 12	Gr 12	Gr 10	Gr 12

From the above biographic information it is evident that the staff in Focus Group 1 is a diverse group in terms of home language, age, vocation and highest qualification achieved, hence heterogeneous perceptions are expected.

Table 3.2 discusses Focus Group 1 according to the participants, the aims, the method used, and the analysis and results of the transcripts, as well as the implications for the development of a sexuality and relationship training programme.

Table 3.2: Participants, aims, method, analysis, results and implications during the Focus Group 1

Category	Description
Participants	<p>A residential care facility for adults with multiple disabilities in the Gauteng province was selected, which employs 57 staff members. All staff members were invited, except caregivers, as they formed a distinct group and participated in Focus Group 1. Staff from both the day and the evening shift could participate, depending on their availability and their willingness to participate in the focus group. This ensured inclusion of staff at different levels, with different occupations and tasks within the residential care facility, for example, instructors in the therapy house, the social worker, the supervisor in the laundry, etcetera.</p> <p>Their biographic details are shown in Table 3.1. Ten participants consented and participated, which is in line with the group sizes of six to 12 participants mentioned in the literature (Kroll, Barbour & Harris, 2007). The fact that the participants knew each other quickly established rapport, creating a social environment that was non-threatening, thereby increasing the quality and richness of the data (McMillan & Schumacher, 2010). The focus group was facilitated by a facilitator and co-facilitator, who also acted as a scribe.</p>
Aims	<p>Seven open-ended questions were asked in a semi-structured format to explore the perceptions of participants related to sexuality and to encourage them to respond from their own working experience. In addition, staff was also asked to suggest possible contents for the sexuality and relationship training programme. The specific questions were:</p>

Category	Description
	<ul style="list-style-type: none"> • <i>Watter belangrike aspekte dink jy bring die rolprent oor die sosiale storie na vore oor verhoudings en vroue met intellektuele gestremdhede?</i> [What important aspects do you think the social story movie highlights with regards to relationships and women who have an intellectual disability?] • <i>Wat beteken die woord “seksualiteit” vir jou?</i> [What does the word “sexuality” mean to you?] • <i>Wat dink jy verstaan vroue wat geringe tot matige intellektuele gestremdhede het rakende hul eie seksualiteit?</i> [What do you think women with mild to moderate intellectual disabilities understand about their own sexuality?] • <i>Hoe kan ‘n opvoedkundige program oor seksualiteit bydra tot die lewens van vroue met geringe tot matige intellektuele gestremdhede?</i> [How could a training programme on sexuality education contribute to the lives of women with intellectual disabilities?] • <i>Watter tipe inhoud wat verband hou met seksualiteit moet ingesluit word in ‘n program vir vroue met geringe tot matige intellektuele gestremdhede?</i> [What type of content related to sexuality is important to include in a training programme for women with mild to moderate intellectual disabilities?] • <i>Watter ander aspekte wat aansluit by die seksualiteit van vroue met geringe tot matige intellektuele gestremdhede het julle al mee te doen gehad by die sentrum?</i> [What type of issues have you had to deal with related to the sexuality of women with mild to moderate intellectual disabilities while working at the centre?] • <i>Watter addisionele inligting sal jy voordelig vind om in ‘n opvoedingsprogram in te sluit oor seksualiteit?</i> [What additional information would you find beneficial to include in a sexuality education programme?]
Method	<p>Written informed consent was obtained beforehand from all participants. At the beginning of the focus group session, the facilitator explained the purpose of the research. Participants were informed about the procedure of the focus group and reminded that their participation was voluntary and that they were allowed to discontinue their participation at any given time without any negative consequences. They were also reassured that the data was confidential and that it is important that they do not reveal the content of the discussion to others outside the group (Overlien, Aronsson & Hyden, 2005).</p> <p>The facilitator then introduced the topic by using a clip from a social story movie as the stimulus material (http://www.the-specials.com; Overlien et al., 2005). Participants were informed that the discussions would be audio recorded in order to facilitate accurate transcription by the researcher. In addition, the co-facilitator took field notes to facilitate data analysis. Although the participants requested that the focus group session be conducted in English, they spontaneously code-switched to Afrikaans. Therefore, the focus group is bilingual, and the research was done both in English and Afrikaans. The facilitator led the focus group in both an English and Afrikaans semi-structured discussion of the open-ended questions to provide structure (Krueger, 1988). During the discussion, the facilitator provided clarification of concepts when needed and when data were open to misinterpretation. The facilitator translated each question into Afrikaans to accommodate some of the participants who were Afrikaans-speaking.</p> <p>The participants were encouraged to share ideas openly, on the understanding that they could answer in the language in which they felt comfortable (Overlien et al., 2005). The interaction between participants provided the facilitator with an opportunity to study the process of collective sense-making and to learn the language and vocabulary used by participants (Frith & Frith, 2001). The facilitator summarised the salient points that emerged after each question had been discussed and verified her understanding of these points with the participants, also asking them if there was any further contribution they would like to add. This type of member-checking enhanced the trustworthiness of the data. After the focus group session, the researcher and her co-facilitator spent time debriefing and sharing their respective interpretations. This also contributed to the trustworthiness of the data.</p>

Category	Description
	<p>A verbatim transcription of the focus group session was made by the researcher and the facilitator, and lasted 180 minutes – longer than the suggested time of 90-120 minutes (McMillan & Schumacher, 2010). Additional time had to be allocated to explain and complete informed consent letters as well as biographic questionnaires. The researcher audited each transcript against the original audio tape. This stringent process increased the procedural integrity of the transcripts (Boyatzis, 1998).</p>
Analysis	<p>The researcher delineated themes from the focus group transcriptions and came to tentative conclusions. The transcriptions were then handed to the co-facilitator, who was asked to also delineate themes. Translations of the transcript of the focus group were done according to the analysis continuum of Krueger (1998). The raw data were transcripts, or abridged transcripts, that present the exact statements of the focus group participants as they responded to the specific questions in the discussion (Krueger, 1988).</p> <p>Next on the continuum are the description or summary statements of participants representing only a few typical quotes, providing a brief description of theme/s per question, followed by verbatim quotes that will illustrate the different themes (Krueger, 1988). The interpretation of the data is more complex and builds on the foundation of the descriptive statements, suggesting what the findings mean. This process aims at providing understanding. Interpretation is always rooted in the raw data. The interpretations presented are directly linked to raw data evidence in the focus group (Krueger, 1988). For a complete transcription of the results, please refer to Appendix B.</p>
Results	<p>A synopsis of the results showed that the role that staff play in the day-to-day living of women with intellectual disabilities can have a substantial influence on how they express their sexuality. Participants expressed a need to teach women with intellectual disabilities how to express themselves in an appropriate manner, although they acknowledged that the sexual expression of women with intellectual disabilities is still seen as a taboo subject.</p> <p>Often there is no opportunity for these women to form their sexuality or maintain healthy relationships. This suggests that if they are prevented from having age-appropriate sexuality experiences, it might lead to sexually inappropriate behaviour, such as touching another improperly (Grievoe et al., 2007). Couwenhoven (2007) confirms that touch and affection errors occur because individuals with intellectual disabilities lack information or are unable to generalise information from one relationship, situation or context to another.</p> <p>The staff's inability to conceptualise the basic needs and meaning of "sexuality", in that an individual's sexual development is based on a multidimensional process, was evident. The basic needs include "being liked" and accepted (self-worth), displaying and receiving affection (appropriate touch), feeling valued (self-esteem – one's attitude towards oneself) and attractive (self-concept features) and sharing thoughts and feelings (intimacy).</p>
Implications	<p>The implications of the results are important for redefining strategies for solutions. From the beginning, participants stated that the concept "sexuality" was new to them, and that they thought that "sex" and "sexuality" has exactly the same meaning. Participants could not relate the social story movie to the first question, and it seemed that they did not fully understand the questions. Participants clearly identified that they felt inadequate about the behaviour of the women with intellectual disabilities related to sexuality and how they should "handle it", and that they would welcome more knowledge and skills.</p> <p>Although staff thought that participants were well aware of appropriate versus inappropriate sexuality behaviour, the ongoing misconception of sex versus sexuality was evident, which made it difficult to elicit accurate responses to the specific questions. The focus group provided the researcher with a rich description of the context and a deeper understanding of the issues at hand. However, it also made the researcher aware of how significant attitudes toward the sexuality of women with intellectual disabilities are, and that if negative and misperceived, this could be detrimental to the sexual identity and interpersonal relationships of these women. There is a need</p>

Category	Description
	<p>to teach women with intellectual disabilities how to express themselves in an appropriate manner, and acknowledge that the sexual expression of women with intellectual disabilities is still seen as a taboo. Often there is no opportunity for women with intellectual disabilities to form or maintain their sexuality. This suggests that if they are prevented from having age-appropriate sexuality experiences, it might lead to sexually inappropriate behaviour such as touching others improperly (Grieveo, et al., 2008). Couwenhoven (2007) confirms that touch and affection errors occur because individuals with intellectual disabilities lack information or are unable to generalise information from one relationship, situation or context to another.</p> <p>The staff's inability to conceptualise the basic needs and meaning of "sexuality", that an individual's sexual development is based on a multidimensional process, was evident. The basic needs include "being liked" and accepted (self-worth), displaying and receiving affection (appropriate touch), feeling valued (self-esteem – one's attitude towards oneself) and attractive (self-concept – features) and sharing thoughts and feelings. Our understanding about what it means to be a male or female, to be sexual, to be attractive or to have a disability, influences how we act or respond in different environments (Couwenhoven, 2007).</p> <p>Varying needs for touch and affection are necessary and beneficial to all human beings. Most of us have learned over time to have these needs met in socially accepted ways. Touch and affection could seem out of place as a result of the behaviour that does not match what society expects from adult women with intellectual disabilities. Women with intellectual disabilities are often "programmed" by their parents, caregivers and staff to express their affection inappropriately, simply because of their disabilities. This increases the vulnerability of women with intellectual disabilities to sexual abuse and exploitation. How do we assist them to express closeness and affection in socially acceptable ways without depriving them from touch?</p> <p>Brantlinger (1983) argues that the rights of individuals with intellectual disabilities are governed invariably, not by the law, but by the feelings (attitude) and behaviours of the people who care for them. Furthermore, Cuskelly and Bryde (2007) conducted a study examining parents, support staff and a community sample of university students' attitudes towards the sexuality of individuals with moderate learning disabilities. The results of the study showed that age was the most important variable, with older participants showing the most liberal attitudes (Cuskelly & Bryde, 2007). Dominant voices within the focus group made it clear that they firmly believe that a training programme would make no difference to the knowledge of women with intellectual disabilities about their own sexuality. When exposed to negative attitudes, a human being with or without disabilities will learn that sexuality is a negative or unacceptable aspect of who he or she is.</p> <p>Couwenhoven (2007) confirms that individuals with disabilities are less likely to ask questions or engage their parents in conversations prompted by curiosity. This allows parents and caregivers to postpone teaching. According to Couwenhoven (2007), sexuality involves most topics that involve an understanding of public versus private concepts. Children with intellectual disabilities need more time to master toileting, bathing and dressing skills, requiring their parents or caregivers to be in their personal space for longer periods of time than typically required for developing children. In addition, children with intellectual disabilities take longer to develop and learn socialisation skills, which means that parents and caregivers watch, supervise and intervene a bit longer, and this tends to continue into adulthood.</p> <p>The increased supervision and ongoing surveillance is often a part of life that creates an altered script that makes learning and understanding privacy concepts more difficult. This desensitises the person with an intellectual disability to the concept of "privacy" and its meaning, and the confusion often leads to difficulties discriminating between public and private concepts. Carers expressed ambiguity towards same-sex sexual activities. According to Evans et al., (2009), staff and caregivers might misinterpret homosexuality as friendships or misdirect expressions of affection</p>

Category	Description
	(Lofgren-Martenson, 2012). This directly undermines the human rights of these women to explore and develop their own sexual identity and preferences (Evans et al., 2009). Results without disability usually keep some physical and emotional distance from acquaintances and strangers, and they have the ability to adapt their levels of touch and affection based on the relationships they have with a specific person. On the other hand, adults with intellectual disabilities typically need considerable guidance with this social skill. Labelling relationships for individuals with intellectual disabilities and helping them to understand different ways of greeting or types of affection within these relationships can contribute significantly to their lives in becoming more socially appropriate.

From Focus Group 1 it is evident that staff members play an important role in the daily lives of women with intellectual disabilities and that, based on their own sexuality, they can have a substantial influence on how these women express their sexuality. The staff's inability to differentiate the meaning of "sex" and "sexuality" was evident. A gap was identified in the basic knowledge regarding sexuality and relationships, such as "being liked" and accepted (self-worth), displaying and receiving affection (appropriate touch), feeling valued (self-esteem – one's attitude towards oneself), feeling attractive (self-concept – features) and sharing thoughts and feelings (intimacy).

3.3.2 Focus Group 2 with Caregivers of Women with Intellectual Disabilities

Following Focus Group 1 with the staff of a residential care facility, Focus Group 2 was conducted with the caregivers of the women with intellectual disabilities in the same residential care facility. This focus group had exactly the same main aim as Focus Group 1, as a different perspective was sought. The biographic information of the participants of Focus Group 2 is presented in Table 3.3.

Table 3.3: Biographic information of caregivers who work with women with intellectual disabilities (N=5)

Category	P2.1	P2.2	P2.3	P2.4	P2.5
Gender	F	F	M	M	F
Age	38 years	54 years	45 years	23 years	61 years
Home language	Setswana	Afrikaans	Afrikaans English	Afrikaans English	Afrikaans
Religious affiliation	Christian	Christian	Christian	Christian	Christian
Church attendance	Once a week	Once a month	Once a month	Once a month	Once a month
Years employed at the facility	8 years	5 years	11 years	2 years	3 years
Total hours per day working with women who have an intellectual disability	8 hours	8+ hours	6 hours	2 hours	8 hours
Have you ever spoken to the women about sexuality?	Yes	No, the sister at the clinic did, they must use condoms and	Yes	Yes	Yes

Category	P2.1	P2.2	P2.3	P2.4	P2.5
		not sleep around.			
Have the women been exposed to sexuality education that you are aware of? Please specify	Yes, as part of Health & Safety training	No	Yes, as part of HIV training	Yes, in the therapy house	Yes, in the therapy house
Awareness of existing sexuality policy of the facility	Yes	Yes	Yes	Yes	Yes
Support of sexuality policy? Explain why.	Yes, sexuality is a human need.	Yes, sexuality is a human need of all people.	Yes, sexuality is a human desire and a human right.	Yes, sexuality is a human need – but only between certain individuals.	Yes. Although disabled, the residents still have a need to be loved and to feel secure; they do get involved in relationships and have the need to be loved and feel secure. When in a relationship, sex is natural.

Following the results from Focus Group 1, the list of biographical questions asked to participants in Focus Group 2 was expanded, as it was felt that this might provide a deeper, richer understanding of the results and how to interpret them. It is evident from Focus Group 2 that from the above biographical data, the knowledge and training of caregivers about the difference between sex and sexuality of women with intellectual disabilities is taken for granted. In addition, it is accepted that caregivers make women with intellectual disabilities aware of the concept of themselves as being sexual beings.

In Table 3.3, Focus Group 2 is discussed in the same manner as Focus Group 1 had been described in Table 3.2.

Table 3.4: Participants, aims, method, analysis, results and implications during Focus Group 2

Category	Description
Participants	There were ten caregivers (some working during the day and some during the night) who provide direct care to the women with intellectual disabilities at the particular residential care centre and who could thus potentially participate. Potential participants were selected with the assistance of the social worker, based on the following criteria: caregivers functioning within different sections of the centre, such as the therapy house, the frail-care ward and the female hostels and availability (some caregivers were required to accompany some of the residents during hospital visits). This resulted in five potential participants. All consented to participate. A detailed description of these participants' biographical backgrounds is shown in Table 3.3. As with Focus Group 1, participants knew each other, which led to rapport and trust being established.
Aims	The aim of this focus group was exactly the same as for Focus Group 1, and the same seven open-ended questions were used, following the same semi-structured format.
Method	The same method explained for Focus Group 1 was utilised, except for Step 1. All concepts were defined before the discussion was initiated, as it was obvious from Focus Group 1 that participants were not familiar with the concepts and were unable to differentiate between "sex" and "sexuality".
Analysis	Data analysis was done according to the same method discussed in the Focus Group 1 (please see Table 3.2).

Category	Description
Results	<p>It is evident that the majority of participants did not have a broad understanding related to the difference between the concept of sex and sexuality of women with intellectual disabilities living within residential care facilities. The contexts were more related to intimacy-related incidences of women with intellectual disabilities and much less frequently education related, and concerned mainly the women with intellectual disabilities' intimacy practices within relationships as well as promiscuity, but more on a minor level.</p> <p>The participants mentioned various types of behaviour, mainly verbal taunts of a sexual nature, as well as exhibitionism and less frequently, masturbation. From the participants it is understood that observed abnormal behaviours did not cause any emotional reactions from them as caregivers. The participants most frequently endorsed the medical model of sexuality and intellectual disability. In addition, the caregivers largely focused on the necessity to normalise the lives of the women with intellectual disabilities in the residential care facility to the extent that they justified these women's functioning in a natural environment and not in social isolation.</p> <p>The caregivers reflected the perception that intellectual disabilities were largely complex conditions of a biological nature, which led to the conviction that only specialists on a medical level, such as the nursing staff, were needed in the process to support women with intellectual disabilities. Beliefs expressed by participants regarding women with intellectual disabilities having "sex" were mostly characterised normalisation. The role of environmental factors were stressed as a contributing factor (the process of being socially isolated), being limited to meeting other people within their limited social context – even non-disabled potential partners. A characteristic feature here is that the role of sexuality education is perceived harmful, as it may "awaken sexuality needs."</p>
Implications	<p>Opportunities for women with intellectual disabilities to participate in focus groups to include their voices in sexuality and relationship education programmes are often constrained by the attitudes and perceptions of caregivers within residential care facilities. In order to understand how the barriers might be removed, firstly the need to protect women with intellectual disabilities; the lack of training of caregivers within residential care facilities; the scarcity of educational and effective resources; and cultural inhibitions need to be emphasised (Lafferty, McConkey, Simpson & Wheeler, 2012).</p> <p>To be able to lessen the impact of these barriers, a six-stage process, as mentioned in 3.2.3, is suggested in developing guidelines for residential care settings to empower caregivers in the drafting of a policy into an accessible, understandable format for individuals with intellectual disabilities, is seen as an essential part of policy development. There are considerable societal obstacles experienced by women with intellectual disabilities with regard to education around sexuality and relationships (Lafferty et al., 2013). This is especially ironic, given the high priority women with intellectual disabilities place on having friendships and the desire of being more knowledgeable about sexuality (Healey et al., 2009; Siebelink et al., 2006).</p> <p>A step towards achieving increased opportunities for women with intellectual disabilities is access for caregivers to sexuality and relationship education programmes to have a better understanding of the influences that could shape their perceptions and to discover areas of consensus on which a common approach can be built (Lafferty et al., 2013). Two major sources of influences can be identified. The first is the ethos of protection that surrounds women with intellectual disabilities deemed to be vulnerable. Some attempts have been made to improve the equality of access for women with intellectual disabilities to ensure the same opportunities as those afforded to women without disabilities. However, the notions of "special needs" and "protection" still leave women with intellectual disabilities largely segregated from many activities in society. Anderson and Kitchin (2000) argue that the lives of women with</p>

Category	Description
	<p>intellectual disabilities are often portrayed as constrained and even deviant. Moreover, the current provision and regulation of care services assume that women with intellectual disabilities need to be protected from abuse. Furthermore, it is presumed especially by caregivers within these residential care facilities that these women are not capable of consenting to intimate relationships (Lafferty et al., 2013). The concepts of “special needs” and “protection” tend to be dominant, and there is less concern for the legal and human rights. A second major influence derives from a religious and moral climate of the society in which people live. Sexuality and intimate relationships with women with intellectual disabilities are a sensitive issue that can potentially militate against an open and honest acceptance and discussion of sex and sexuality among caregivers within a residential care facility (Rolston, Schubotz & Simpson, 2005).</p> <p>This conservatism with regard to sexual expression is particularly evident concerning women with intellectual disabilities who are perceived as perpetual children who need to be protected from knowledge related to sexuality and intimate relationships that may lead to inappropriate experimentation (Ryan & McConkey, 2000). Therefore, education and support around sexuality and intimate relationships tend to be ignored and often to avoid personal embarrassment or disagreements among caregivers. Paradoxically this stance discounts the protection that knowledge about sexuality and more socially appropriate behaviour provides to women with intellectual disabilities that have an increased vulnerability to sexual abuse (O’Callaghan & Murphy, 2004).</p> <p>Hence, caregivers have a significant role to play in the sexuality and relationship education of women with intellectual disabilities within residential care facilities. Lafferty et al. (2013) identified the variations in attitudes within work settings of caregivers, personal values and access to training that contribute to the support in sexuality and relationship education of women with intellectual disabilities. Although there is often no formal requirement for the caregivers to provide sexuality and relationship education for the women, they are well placed to respond to the needs of the women they support on an informal basis.</p>

From Focus Group 2 it became evident that caregivers need to be equipped with knowledge and skill regarding sexuality in order to facilitate the development of appropriate social skills for women with intellectual disabilities living in residential care facilities. Caregivers seem to be the main educators for socially appropriate skills through role modelling.

3.3.3 Focus Group 3 with Women with Intellectual Disabilities

Following the previous two focus group sessions, a third focus group was conducted; this time with women with moderate intellectual disabilities who reside in the residential care facility. The main purpose of this focus group was to provide these women with the opportunity to share their knowledge about their sexuality and relationships, and to make their voices heard. Research has shown that including participants from the primary stakeholder group (in this case women with intellectual disabilities) provides researchers with increased insights, such as how the disability influences their sexuality, how they express their sexuality and how they came to learn about sexuality (Bernert, 2011;

Bleazard, 2010; Miodrag, 2004). Therefore, a paradigm shift is needed that acknowledges this involvement, and that the institutional practices and policies of residential facilities need to be challenged so that the discourse that involves the stakeholder group can be encouraged (Bernert, 2011).

To recruit possible participants for Focus Group 3, three selection criteria were used, namely:

- All participants had to live in the residential care facility during the week, as they had direct interaction with their caregivers on a daily basis for training purposes.
- All had to have a chronological age of 18 years or older (as age has legal implications in terms of sexual relationships).
- Only female participants were included, as they have a double disadvantage of being the victims of abuse, because of the fact that they are women, and the fact that they are disabled (Lafferty, McConkey, Simpson, & Wheeler, 2012). Their heightened vulnerability makes them the focus of this research.

The biographic information of the women with intellectual disabilities who reside in the residential care facility, and who participated in Focus Group 3, is presented in Table 3.5.

Table 3.5: Biographic information of Women with Intellectual Disabilities (N=10)

Participants	P3.1	P3.2	P3.3	P3.4	P3.5	P3.6	P3.7	P3.8	P3.9	P3.10
Etiology	Acquired	Genetic	Genetic	Genetic	Acquired	Genetic	Develop- mental	Genetic	Acquired	Develop- mental
Age	51 years	55 years	40 years	25 years	23 years	45 years	47 years	42 years	45 years	48 years
Language	Afrikaans	English	Afrikaans	Afrikaans	English	Afrikaans	Afrikaans	Afrikaans	Afrikaans	Afrikaans
Education	Grade 5	Grade 8	Unknown	Group 7	Grade 9	Unknown	Grade 8	Level 5	Level 2	Grade 10
Religious affiliation	Christian	Christian	Christian	Christian	Christian	Christian	Christian	Christian	Christian	Christian
Church attendance	More than once a week	Once a week	More than once a week	Once a week	Once a month	Once a week	More than once a week	Once a week	Once a week	Once a week
Period staying in the centre?	28 years	36 years	19 years	3 years	1 year	18 years	29 years	23 years	21 years	23 years
Boyfriend currently	Yes	No	No	Yes	Yes	Yes	No	Yes	Yes	Yes
Boyfriend before	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No response	No
Been on a date	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Formal sex education	No	No	Yes	Yes	Yes	Yes	Yes	No	No	Yes

Participants	P3.1	P3.2	P3.3	P3.4	P3.5	P3.6	P3.7	P3.8	P3.9	P3.10
If yes, by whom?	n/a	n/a	Mother	Clinic	Mother, school	Teacher	Mother	n/a	n/a	Mother
Focus of sex Education programme	No response	No response	General	Use condoms to be safe and prevent HIV, have safe sex and prevent from having babies	Safety HIV/Aids Babies	Use condoms	Does not spend time alone with boys	No response	No response	Conception
Awareness of sexuality policy	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Support of sexuality policy	Yes	Yes	Yes	Yes, it is a good thing because your life depends on it	Yes, rather sorry	Yes, cleanliness	Yes	Yes	Yes	Yes

It is evident from Table 3.5 that all women with intellectual disabilities stated that they currently have a boyfriend or that they have previously had one. In addition, the training of sexuality education is reflected by only six of the participants. Finally the awareness of the sexuality policy of the residential care facility is confirmed by all the participants, as well as their supporting it.

In Table 3.6, the Focus Group 3 session, which was held at the same facility as the previous two focus groups, is discussed. Only information different from the previous two focus groups is highlighted.

Table 3.6: Participants, aims, method, analysis, results and implications during Focus Group 3

Category	Description
Participants	Ten women with intellectual disabilities who met the selection criteria described earlier were selected with the assistance of the social worker to attend the focus group session. It was scheduled on a Thursday at 09:30, a time the residents considered convenient. All ten women assented, and verbal consent was obtained telephonically from parents and legal guardians by the social worker on the morning before the focus group session took place. The social worker, as well as the director of the residential care facility, signed each informed consent slip as legal guardians to each participant. All ten of the potential participants were able to attend the focus group session. The biographical background details of all ten participants are shown in Table 3.5.
Aims	To explore the participant's perceptions, the exact same seven questions that were used in the previous two focus groups were used again, although the questions were phrased differently to enhance understanding. <ul style="list-style-type: none"> • Wat is die verskil tussen "seks" en "seksualiteit"? [<i>What is the difference between "sex" and "sexuality"?</i>]

Category	Description
	<ul style="list-style-type: none"> • Wat dink julle is belangrik in 'n liefdesverhouding? <i>[What do you think is important in an intimate relationship?]</i> • Wat dink jy beteken seksualiteit vir van jou vriendinne in die sentrum? Dink jy hulle weet wat seksualiteit beteken? <i>[What do you think sexuality means to some of your friends in the centre?] Do you think they know what sexuality means?</i> • Dink julle 'n program oor verhoudings, enige soorte verhoudings, oor hoe om op te tree, verskillende soorte aanrakings, aanrakings wat jou dalk ongemaklik kan laat voel, enige optrede in die publiek, vreemdelinge wat aanmerkings maak: dink julle 'n program kan dalk help om mense se gedrag te verbeter? <i>[Do you think a programme about relationships, any type of programme, about how to behave, different types of touch, touch that might make you feel uncomfortable, any behaviour in public, strangers that make remarks: do you think any programme will help to improve people's behaviour?]</i> • Wat dink julle sal belangrik wees om in so 'n program te hê, byvoorbeeld: "Ek mag nie 'n romantiese verhouding met my oom hê nie want hy is familie, maar ek mag 'n verhouding met (naam) hê". Nog 'n voorbeeld is wanneer 'n vreemdeling besigheid by die sentrum kom doen, kan een van die inwoners nie net op die persoon afstorm en hom of haar omhels en soen nie. So wat dink julle sal belangrik wees in 'n program wat die inwoners moet leer wat hulle gedrag sal verbeter? <i>[What do you think is important to include in such a programme? For example, "I am not allowed to have an intimate relationship with my uncle because he is a relative, but I can have an intimate relationship with [name]". Another example is when a stranger visits the centre to do business, one of the residents cannot just approach the person and hug and kiss him or her. So what do you think is important to be in a programme you think the residents should learn that could improve their behaviour?]</i> • Waarvan wil julle meer leer? <i>[What do you want to learn more about?]</i> • Wat dink julle moet nie in so 'n program wees nie? Wat dink julle sal meer konflik of 'n probleem veroorsaak? Wat sal julle verkies om nie oor te praat nie? <i>[What do you think should not be in such a programme? What do you think will cause more conflict or a problem? What would you prefer not to talk about?]</i> • Wat is belangrik oor verhoudings wat julle in die fliek gesien het? <i>[What is important about relationships that you saw in the movie?]</i>
Method	<p>In order to establish a relaxed non-threatening environment, the participants enjoyed fruit juice and cupcakes before commencing with the session. The focus group was conducted in the mother tongue of the group, namely Afrikaans. Although the participants could not provide written informed consent, assent was explained and obtained from all the participants with the support of picture symbols (Appendix E). Consent was obtained from their legal guardians prior to the focus group session, as explained earlier. The picture symbols explained to the women and enhanced their understanding and purpose of the focus group.</p> <p>Confidentiality, voluntary participation, and the fact that they could terminate participation at any point without negative consequences, were also explained with the support of symbols. Participants were informed that the discussions would be audio recorded in order to facilitate accurate transcription by the researcher. The social worker assisted the researcher with completing the assent letters and the biographic questionnaires, as the participants were not functionally literate.</p> <p>The facilitator led the focus group in Afrikaans, as it was the majority of the group's home language and the preferred language of discussion. The previous two groups alternated between English and Afrikaans. Before commencement of the discussion, the following specific concepts were highlighted and the participants' understanding of the concepts was enhanced by using clips from magazines, for example: friends' versus strangers; romantic relationships versus friendships; and public places versus private places. When participants struggled to express themselves or to understand the researcher, questions were rephrased and clarifications given. The initial questions were of a more general nature.</p>

Category	Description
	<p>Participants were also encouraged to ask questions of their own. To enhance further understanding, the researcher used props in a gift bag given to each of the participants. The researcher then asked each participant to remove the butterfly fridge magnet from their gift bags and explained that the fridge magnet can be compared to the different relationships we have in our lives. She then demonstrated that the paperclip can attach itself to the magnet (which could signify romantic relationships), compared to the pen that is not attracted to the magnet (which could signify a relationship with a stranger). The above adjustments were made as a result of this group's unique group needs.</p> <p>After this a comfort break was allowed, as some of the participants wanted to go to the bathroom while others requested a smoke break. This part of the focus group session lasted 180 minutes, and was not transcribed verbatim, although an audio recording was made in order to familiarise the participants with the procedure and equipment.</p> <p>The topic was then introduced by the facilitator and initiated with the same social story movie clip described earlier. During the discussion, the facilitator provided clarification when some concepts were unclear. For example, with question 3: "How will a training programme help you to understand sexuality and relationships better?" The researcher elaborated on this and translated the following into Afrikaans: "<i>Dink julle 'n program oor verhoudings, enige tipe verhoudings, oor hoe om op te tree, verskillende soorte aanrakings, aanrakings wat jou dalk ongemaklik laat voel, enige optrede in die openbaar, vreemdelinge wat aanmerkings maak, dalk kan help om mense se gedrag te verbeter?</i>" [Do you think a programme about relationships, any type of relationships, how to behave, and different types of touching, touching that makes you feel uncomfortable, any behaviour in public, strangers making remarks: do you think a programme can perhaps help to improve individuals' behaviour?] The facilitator translated some questions into English to accommodate one of the participants who was English-speaking and who needed clarification on some of the questions. A verbatim transcription of the focus group was made.</p>
Analysis	<p>Thematic analysis was used to analyse the raw data, focusing on themes identified by coding, to discover recurrent patterns, as was done in Focus Group 2.</p>
Results	<p>Exploring the women's construction of sexuality, the conversations consisted mostly of their perceptions and views of sexuality and personal experiences. The facilitator and the social worker collectively explained concepts that were not understood by the women, for example, "training programme" and in Afrikaans "opvoedkundige program". The presence of the social worker was essential, as she was more familiar with the language difficulties experienced by some of the women with intellectual disabilities. Her presence also made the women feel more at ease, as she was familiar to them.</p> <p>Some women shared experiences unprompted and in the context of other conversations. Themes represent women as a collective group and do not include data identifiable to any one particular woman. The majority of the women did not seem to identify themselves as having a disability, but rather as being women. How sexuality was constructed by the caregivers that participated in Focus Group 2 was in stark contrast to the perceptions of the women in Focus Group 3. The women conveyed understanding of their own personal values within a romantic relationship, as well as what their personal needs were. Six questions were extrapolated from the questions asked by the women in the groups, concerning what they would want from an educational training programme regarding sexuality and relationships. The questions were as follows:</p> <ul style="list-style-type: none"> • What is the difference between other relationships and a romantic relationship? • What is the correct way to behave in a romantic relationship? • What is acceptable behaviour for a man in a romantic relationship? • What is acceptable behaviour for a woman in a romantic relationship? • What is allowed in a romantic relationship?

Category	Description
	<ul style="list-style-type: none"> • What is not allowed in a romantic relationship? <p>It was evident from the discussion that the women can manage their sexuality in some ways by engaging in healthy sexual behaviours, such as having informed judgment about condom use and contraception. Most of the participants had been in relationships before, or were currently in hetero-sexual relationships with one participant being in a same-sex relationship. All expressed having an interest in having such intimate, romantic relationships. The importance of companionship, trust and security in relationships were raised by some of the participants. Most of the participants reported some degree of personal and physical intimacy, for example, holding hands, kissing and also intercourse. The sense of self-esteem was mentioned as a gain from such a relationship. However, disapproval of same-sex relationships was expressed. Most of the participants had relationships within the residential care setting. Six out of the ten participants received either formal or informal sex education from school or a family member. Most participants understood contraception and its role in preventing pregnancy. Condoms were specifically preferred as a preventative method. There was some awareness of the transmission of sexually transmitted diseases and the use of condoms in the prevention thereof.</p>
Implications	<p>Social exclusion because of their disabilities leads to limited social skills and knowledge about sexuality and sexual expression. It seems as if the existing policy related to sexuality is an attempt to mediate the dilemma management and staff experience when balancing the social and sexuality integration of women with intellectual disabilities with safety and support services (Bernert, 2011).</p> <p>Supporting women with intellectual disabilities in ways that will enhance their social skills with an effective education programme requires that their sexuality be better understood and that the disconnect between the women and their direct caregivers be addressed. There is a need for the development of sexuality and relationship related training programmes that are supportive of the sexuality of women with intellectual disabilities, and that can address their unique needs by not only educating them, but also their direct caregivers.</p> <p>Providing women with intellectual disabilities their right to sexuality education can affect their relationships, self-esteem, emotional growth and social behaviour (Bernert, 2011). In addition, normalisation is a restrictive principle when applied to sexuality and women with intellectual disabilities. Brown (1994) expresses the view that that what is considered as “normal” is determined by socialisation and variation in the expression of sexuality that is not freely accepted. In order to be considered able to engage in the expression of one’s sexuality and an intimate relationship, women with intellectual disabilities are expected to have achieved autonomy and self-determination in aspects of living that are rarely obtained by individuals with intellectual disabilities (Healy et al., 2009).</p> <p>Inadequate discussion of sexuality education leads to insufficient knowledge about sexuality and relationships that could lead to a compromised understanding of sexual consent and the inability to distinguish abusive from non-abusive relationships, and are therefore highly vulnerable to sexual abuse and exploitation.</p> <p>The provision of sexuality education on an ongoing basis and the promotion of positive attitudes towards appropriate expression of sexuality are critical to the realisation of sexual autonomy for women with intellectual disabilities. Moreover, tailored sexuality education improves socio-sexual knowledge and has the potential to improve sexuality decision-making skills related to relationships, healthy boundaries, dating and knowing the difference between concepts, such as public and private.</p>

The contrasting information obtained from Focus Group 3, when compared with the previous two focus groups, reiterates the critical importance and value of stakeholder opinion. From Focus Group 3 it was

evident that there are many misconceptions between Focus Group 1 and 2, regarding how the women with intellectual disabilities view their sexuality. Being a woman with an intellectual disability who lives in a residential care facility can mean a lack of privacy, a lack of control with regard to decision making, lack of access to further adult education, limited economic independence, being tested on deficits and not on strengths, being seen as “other”, being a “captive of care”, having to be “grateful” and compliant, being at higher risk of abuse, and having limited means of communication – all aspects that increase vulnerability and perpetuate dependence on others (Gomez, 2012). Social barriers experienced by women with intellectual disabilities entail more than only social attitudes (Gomez, 2012). They also arise from limited social networks and a lack of sexuality training programmes that can equip them with appropriate and relevant knowledge (Gomez, 2012).

3.4 PEDAGOGICAL SYSTEM: DEVELOPMENT OF THE TRAINING PROGRAMME IN TERMS OF CONTENT

The information from the three focus groups was used to inform the development of the training programme. Four main topics were delineated as shown in Table 3.7:

Table 3.7: Application of results from focus groups to the proposed sexuality training programme and outcome goals

Number of aims following focus group outcomes	Application to sexuality and relationship training programme
<p>Introduction The following aims will provide a solid foundation for caregivers to work from by teaching women with intellectual disabilities about sexuality and relationships within different social contexts.</p>	<ul style="list-style-type: none"> • Women with intellectual disabilities are mostly socially isolated and are not always exposed to different social contexts to be able to know what behaviour is socially acceptable.
<p>To teach social boundaries and personal space: by creating awareness of appropriate and inappropriate touching:</p> <ul style="list-style-type: none"> • by reinforcing healthy boundaries in relationships; and • by creating an awareness of the right to say “no”. <p>To teach the difference between the concepts private and public: private versus public places:</p> <ul style="list-style-type: none"> • by creating increased awareness of private and public spaces; and • by describing socially acceptable and desired behaviour. 	<ul style="list-style-type: none"> • Individuals with intellectual disabilities often express affection indiscriminately, which can threaten their social acceptance, increase their vulnerability and sometimes violate the rights of others. • Touch and affection is essential to human life: critical to physical, social and emotional development. • Touch and affection errors made by individuals with intellectual disabilities occur because of a lack of information or the inability to generalise information from one relationship, situation or context to the next. • Individuals with intellectual disabilities have limited life experiences and less information. Their bodies do not always give them signals when they feel unsafe and need to be alert. • Awareness of personal space and the right to decide how much personal space to share and with whom. • Awareness of ownership of their own bodies. Sexuality in its totality almost always involves an understanding of public versus private concepts (Couwenhoven, 2007). Social skills involve knowing certain rules on how to interact and behave appropriately in different situations.
<p>To discuss different types of relationships:</p> <ul style="list-style-type: none"> • by addressing specific characteristics that make relationships healthy and unhealthy. 	<ul style="list-style-type: none"> • Interpreting verbal and non-verbal cues from others: individuals with intellectual disabilities generally have fewer opportunities to generalise skills to real-life settings – understanding how to apply learned skills in a variety of settings contributes to social acceptance. • Encouraging friendship traits, such as honesty, affection, helpfulness, a willingness to listen and compromise, enjoy time spent together and show shared interests. • Information on romantic relationships which implies that two people have sexual feelings for each other. Unacceptable romantic relationships (for example, with a family member or a caregiver) is included.
<p>To improve decision making by establishing, maintaining and terminating a dating relationship.</p>	<ul style="list-style-type: none"> • Explaining the concept of dating. As a planned activity that can assist in decision making regarding healthy and unhealthy relationships.
<p>Conclusion Emphasising the importance of sexuality education. The value of social stories.</p>	<ul style="list-style-type: none"> • Supporting sexuality education. • Creating opportunities for group learning.

In designing an educational training programme, both short and long-term goals should be considered as criteria for evaluating success. For the purpose of this study, the short-term goals are to increase the knowledge of caregivers related to sexuality and relationships so that they would positively impact on

the services provided to women with moderate intellectual disabilities by implementing a tailor-made focused training programme. A positive long-term outcome would be a favourable indication that the training programme is adapted by the residential care facility, as that would be indicative of a possible attitudinal change.

3.5 PROGRAMME DESIGN

The programme was designed to help caregivers to support women with intellectual disabilities to have a clearer understanding of sexuality and relationships by addressing aspects such as appropriate behaviour in public and private places; the ability to differentiate between different types of relationships; appropriate and inappropriate touching; and personal space, as outlined in Table 3.7. Group work is the dominant teaching technique, as the aim of the training programme is to teach skills, attitudes and knowledge needed in real life, making interaction with others essential (Du Toit, Nienaber, Hammes-Kirsten, Kirsten, Claassens, du Plessis & Wissing, 2003).

Social stories have been proven effective as strategies to change target behaviours (Gray, 2003). This is because they provide social information to highlight and teach appropriate, as opposed to inappropriate, social behaviour. Therefore, a social story was developed for each theme of the Sexuality Relationship Training Programme as an important component of behaviour change. Social stories are typically short and written in order to describe an activity (for example, hugging), as well as the anticipated behaviour associated with it (for example, who to hug and when to hug). Most of the time these behaviours are governed by various unwritten and unspoken rules and non-verbal cues, for example, arms folded across the chest means "I don't want a hug". In social stories, social situations and appropriate responses are addressed in a non-threatening way (Del-Valle, McEachern & Chambers, 2001). The fact that social stories provide a concrete method for teaching a skill, using a visual medium, such as pictures, is a strength for many individuals with intellectual disabilities (who are not literate). Furthermore, this is easy to implement, which heightens its suitability for this study (Moyes, 2001). The use of social stories in sexuality training programmes, specifically for individuals with intellectual disabilities who may benefit from overt social rules, therefore appears to be a potentially advantageous intervention tool. Earlier research, although not social-story specific, also showed that the use of specific scenarios (as found in social stories) yielded the most favourable results on exploring results in exploring sexuality for individuals with intellectual disabilities (Evans et al., 2009).

Table 3.8 contains a review of published studies on the use of social stories as an intervention tool to modify, change or decrease inappropriate social behaviour. A literature search was done, using the

search term *social stor* in combination with search terms such as “sex*”, “education”, “intellectual” and “disabil*”. The truncation symbol (*) was used as relevant in the individual databases to maximise the search results. The five databases that were searched included PsycINFO; Educational Resources Information Clearinghouse (ERIC); Science direct; Taylor and Francis; and EBSCO host.

The search results were further delimited to peer review journal status and year of publication (1997-2013). In addition, hand-search documents were included and examined, based on reference lists of retrieved documents cited and unpublished reviews related to social stories, disability and sexuality education. A total of 14 manuscripts were found. Six of these were excluded on the abstract level for the following reasons: one dealt only with task analysis for teaching menstrual care (Klett & Turan, 2012); one dealt with pre-schoolers with autism enrolled in full-inclusion kindergarten classrooms (Chan & O'Reilly, 2008); one dealt with six children between the ages of three and four who had specific language impairments (Pettigrew, 1998); one dealt with individuals with learning disabilities (Kalyva & Agaloitis, 2009); one only dealt with changing problematic lunchtime behaviour related to independently entering the dining-room hall (Toplis & Hadwin, 2006); and one with decreasing disruptive behaviours of children with autism (Ozdemir, 2008). The remaining eight papers were read at full-text level and are summarised in Table 3.8.

Table 3.8 Literature review of social stories in chronological order, starting with the most recent papers (N=8)

Authors & date	Aim	Participants	Use of social story strategy	Significance	Implication for current study
Graetz, Mastropieri & Scruggs, 2009.	To determine the effect of a modified social story on inappropriate social behaviour.	Three adolescents with moderate autism between 12 and 15 years.	Individualised stories were used.	Individualised stories were created for each participant; intervention immediately improved the behaviour of two of the participants; improvement was maintained.	Positive outcomes of desired behaviour; actual use of coloured photographs. Social stories adhered to guidelines regarding the ratio of one directive sentence to two to five descriptive or perspective sentences (Gray, 1995).
Mancil, Haydon & Whitby, 2009.	To compare social story presentations in two formats.	Three elementary children with autism between 10 and 12 years.	Comparing social stories in PowerPoint and paper-based format.	Frequency of problem behaviour decreased; outcomes slightly better for PowerPoint story than for paper format; PowerPoint format was more easily implemented; children preferred PowerPoint format.	PowerPoint story worked effectively. Additional visual stimuli supported individuals and resulted in desired outcomes. Use social stories in PowerPoint format in the present study.
Quimbach, Lincoln, Feinberg-Gizzo, Ingersoll & Andrews,	To increase social skills through the use of social story interventions.	42 children with autism between seven and 14 years.	Social stories were used for game-playing skills.	Individuals with extremely low verbal comprehension skills (based on the WISC-IV) may not benefit from social story	The ability of directive sentences in social stories to prime behaviour in specific contexts describe the importance of providing cues as a conversational support.

Authors & date	Aim	Participants	Use of social story strategy	Significance	Implication for current study
2009.				interventions that do not include pictures or other concomitant treatment strategies.	
Wang & Spillane, 2009.	To provide a synthesis of published research between 1999 and 2009 on interventions to increase social skills; evaluate if given intervention meets criteria for evidence-based practice.	18 children and adolescents with autism spectrum disorder.	Social skills stories were used to determine if they met the criteria for evidence-based practice.	Six of these 38 studies included in the review dealt with social stories to teach social skills. Social stories were one of the intervention types that met all the criteria for evidence-based practices. The percentage of non-overlapping data points) for two of the six social stories intervention studies demonstrated high effectiveness.	Improved social skills are more likely to result in an individual being accepted in integrated settings, to live independently and to work in integrated settings.
Tarnai & Wolfe, 2008.	To investigate the components that make social stories a promising method for intervention, and to discuss the implications of using social stories for sexuality education.	A survey was done of parents and professionals on sexual behaviours of persons with autism or pervasive developmental disorder from 1970 to 2000.	Social stories were used as components for interventions and the implications of utilising them for sexuality education, in particular, instructional use.	Social stories can be used in a general way to prepare individuals for changes and unusual situations as a part of going through stages of sexual development, or they can be written in reaction to evolved problematic situations.	Typical sexuality education programmes for individuals with intellectual disabilities may lack components that address the unique social skills of women with intellectual disabilities.
Quilty, 2007.	To determine if paraprofessionals can be taught to write and implement social stories.	Three children between six and 10 years, and three paraprofessionals participated in pairs.	Social stories were used for paraprofessionals as an effective tool for interventions.	Paraprofessional can be taught how to write and implement social stories; children's problems in behaviours are reduced.	Teaching paraprofessionals to write social stories to address particular behaviours and to implement social stories can have a positive effect on behavioural change.
Ali & Frederickson, 2006.	To review research on social stories published between 1994 and 2004.	46 children between 2 and 15 years. Children between three and 15 years old were studied.	Investigating the evidence base of social stories.	One study involved a training programme spread over two half days, attesting to the effectiveness of relative short-term training. The training programme was run by two educational psychologists for mainstream teachers, learning-support assistants and parents/carers living and working with 15 children with ASD, two with learning	The intervention was effective with children with autism.

Authors & date	Aim	Participants	Use of social story strategy	Significance	Implication for current study
				difficulties, one with Tourette's syndrome and one with semantic pragmatic difficulties.	
Del Valle, McEachern & Chambers, 2001.	To improve social & functioning by addressing appropriate behaviour in social situations and developing problem-solving skills.	Narrative story-telling: listening, telling, re-telling social stories.	Developing problem-solving skills; addressing social situations using social stories.	Social stories were effective in changing behaviour and therefore could also be used to address inappropriate behaviour related to sexuality and social skills.	Personalising social skills training. Modelling social stories appropriate for social skill behaviour. For the women with intellectual disabilities who cannot read, social stories can be audio or video taped. Social stories were effective in changing behaviour and therefore could also be used to address inappropriate behaviour related to sexuality and social skills.

From the literature review shown in Table 3.8, it is clear that social stories can be an effective intervention tool when attempting to change inappropriate or problematic behaviour. However, no published studies could be identified from the literature review where social stories were used in sexuality education for individuals with intellectual disabilities. Most of the studies had been done on children (albeit with different ages) who had an autism diagnosis. However, given the specific population of the current study and the effectiveness of social stories to change behaviour, this seems to be an appropriate methodology.

For the sexuality and relationship education training programme discussed in this thesis, the social stories were written according to specific guidelines developed by Carol Gray (1995; 2000; 2003) from the Gray Centre for Social Learning. Gray suggests the following specific guidelines regarding sentence type to write effective social stories:

- *A descriptive sentence:* This type of sentence tells where the situation occurs, who is involved, what they are doing and why.
- *A perspective sentence:* This sentence describes the reactions and feelings of the individual and of the other people.
- *A directive sentence:* This sentence tells the individual what to do.
- *A control sentence:* This sentence is written from the perspective of the individual having the disability, cueing, how and when to identify personal strategies to recall and to use.

In the current study, all stories included the first three types of sentences, as shown in Table 3.9. The last type of sentence, namely the control sentence, was excluded owing to the low literacy levels of the participants.

Table 3.9: A layout of the four social stories included in the training programme according to the proposed guidelines by Gray (1995; 1997)

Guideline	Social Story 1	Social Story 2	Social Story 3	Social Story 4
1. A descriptive sentence outlining the following:				
1.1 Where does the situation occur?	In public At the mall	Privacy and appropriate conversations in public and the mall	In the community in the neighbourhood	Green-light places (safe places), for example, places such as church, the group home, social groups or friends of friends Red-light places (unsafe places), for example, the mall, the street and parks
1.2. Who is involved?	Caregivers	Strangers	Family Friends Romantic partner Caregivers Neighbours Community helpers Strangers	Someone special, for example, a romantic partner
1.3 What are they doing?	Hugging	Bribing Threatening	Supporting Respecting Dating Assisting Helping	Listening to music
1.4. Why are they doing this?	To show love To show concern	To show that there are different happy and unhappy secrets	To explain that one has different types of relationships with different people	To show that the two partners have the same interests
2. A perspective sentence outlining the following:				
2.1 Reactions and feelings of the individual	Hugs make me feel good	Happy secrets make me feel happy; unhappy secrets are when people want to take advantage of me.	I love and trust my family. I enjoy being with my friends. I have sexual feelings for the person I am in a romantic relationship with	Dating makes me feel excited.
2.2 Reactions and feelings of other people	Other people may feel happy if they are hugged.	Other people might feel happy when they are surprised with a happy secret, for example, a surprise birthday party. Other people might feel unhappy when strangers try to bribe them with gifts or may want to do sexual things with them	The other person has sexual feelings for me if he is in a romantic relationship with me. My friends enjoy being with me; they respect me; they are honest with me and keep their promises	The other person feels comfortable to be with me
3. Directive sentence outlining the following:				
3.1 What should	I should ask permission	Run! Yell! Tell!	I should take ownership	The other person is

Guideline	Social Story 1	Social Story 2	Social Story 3	Social Story 4
the individual do?	before I give someone a hug?		of who is allowed to touch me	interested in getting to know me better

Every directive sentence should be supported by between two and five descriptive sentences and/or perspective sentences (Gray, 1995; 1997). This was suggested as Gray explained that one of the basic premises of the social story approach is that each story should describe, more than direct. She thus proposed the ratio as a last step to determine the proper proportion of sentence type found in the story as a whole, and to ensure a story that describes rather than directs. Social Story 1 has a basic social story ratio of 1:5; Social Story 2 has a ratio of 1:10; Social Story 3 has a ratio of 1:8 and Social Story 4 has a ratio of 2:5.

Furthermore, each of the social stories is related to a specific theme in the Sexuality Relationship Training Programme, and is shown in aSeRT. Social Story 1 is related to Theme 1 (appropriate and inappropriate touching), likewise Social Story 2 is related to Theme 2 (public and private concepts), Social Story 3 to Theme 3 (different types of relationships) and Social Story 4 to Theme 4 (dating).

3.6 PROPOSED TRAINING PROGRAMME

The proposed programme spans a two-day period and is intended for caregivers of women with intellectual disabilities. Day 1 is initiated by an introduction of the overall purpose of the training programme and the aim of the training, followed by a clarification of the myths and misconceptions related to the sexuality of women with intellectual disabilities and emphasising why it is important for caregivers to attend the training. Thereafter, Themes 1 and 2 are trained in separate sessions. Each theme describes the aim of the training, specific learning outcomes, as well as the equipment and instructional method used. In addition, each theme is supported by a theoretical discussion, as well as a practical session that includes an ice-breaker, a social story that is supplemented by a teaching activity to enhance the understanding of women with intellectual disabilities who have difficulties in abstract thinking (Couwenhoven, 2007), a cool-down activity, and a reflection activity at the end of the theme.

Day 2 commences with the training of Themes 3 and 4, following exactly the same layout and method as were discussed for Day 1's training. Day 2 ends with the administering of the post-test to both the experimental and control group. A brief summary of the proposed training programme that spans the two days is shown in Table 3.10. It highlights the specific themes, as well as the aims of the session, the material used and the proposed outcomes for the specific theme.

Table 3.10: Brief summary of the two-day training programme

Slot & Time	Training Session Content
Day 1 Session 1	
08:00 – 08:30	Registration and welcome
08:30 – 09:30	Administer pre-test: experimental and control group
09:30 – 09:40	Brief introduction
09:40 – 10:15	Aim of training, importance of training programme, clarification of myths and misconceptions regarding sexuality and women with intellectual disabilities
Purpose:	<ul style="list-style-type: none"> • Set the context for the day • Generate energy and anticipation
Process:	<ul style="list-style-type: none"> • Participants seated in a U-shape • Introduction by researcher, who explains the four themes, as well as the layout of the different components of the training (ice-breaker, social story, activity and final word and reflection)
Material/Equipment:	<ul style="list-style-type: none"> • Sexuality and Relationship Training Manual • Measuring instrument • Laptop and Proxima projector • Flipchart • Pens
TEA 10:15-10:30	
10:30 – 13:00	Teaching social boundaries and personal space
Theme 1 Aim 1	
Purpose:	<ul style="list-style-type: none"> • To teach caregivers how to empower women with intellectual disabilities with the skill of ownership of their bodies: “giving permission to touch or not to touch”. • To teach caregivers how to teach women to respect personal boundaries. • To teach caregivers how to create an awareness of whom to hug, whom to shake hands with and whom to give a high five to? • To explain to caregivers how to teach women to respond appropriately to different types of touch.
Process	<ul style="list-style-type: none"> • Researcher introduces Theme 1 • Ice-breaker: Greetings permission game • Social Story 1: All about hugs • Activity: Piece of string • Cool-down activity: “Big fish, small fish” • Reflection and final word
Material/Equipment:	<ul style="list-style-type: none"> • Sexuality and Relationship Training Manual • Measuring instrument • Laptop and Proxima projector • Flipchart • Pens
Feedback from group about activities and practical application to real-life situations	
LUNCH 13:00-14:00	
14:00 – 16:00	Public and private places
Theme 2 Aim 2	
Purpose:	<ul style="list-style-type: none"> • To understand the difference between the concepts public and private • To distinguish between appropriate and inappropriate behaviour in a public and private place
Process:	<ul style="list-style-type: none"> • Researcher introduces Theme 2 • Ice-breaker: Road map • Social Story 2: Public and private places • Activity: Collage • Cool-down activity: Labelling • Reflection and final word
Material/Equipment:	<ul style="list-style-type: none"> • Sexuality and relationship training manual • Measuring instrument • Laptop and Proxima projector

Slot & Time	Training Session Content
	<ul style="list-style-type: none"> • Flipchart • Pens <p>Feedback from group about activities and practical application to real-life situations.</p>
Day 2 Session 2	
08:00 – 08:30 08:30 – 10:30 Theme 3 Aim 3 Purpose:	Registration and welcome Different types of relationships <ul style="list-style-type: none"> • To teach the specific characteristics that make relationships healthy and unhealthy. • To improve decision making relating to when to continue and when to end a dating relationship. • To teach relationship concepts. • To teach of social boundaries and how to reinforce them. • Teaching of different types of relationships. • To enhance the understanding of how to apply learned skills in a variety of settings and how it contributes to social acceptance.
Process:	<ul style="list-style-type: none"> • Researcher introduces Theme 3 • Ice-breaker: Attraction versus trust • Social Story 3: Relationship sequencing • Activity: Social boundary circle chart • Cool-down activity: Teaching verbal and non-verbal cues
Material/Equipment:	<ul style="list-style-type: none"> • Reflection and final word • Sexuality and Relationship Training Manual • Measuring instrument • Laptop and Proxima projector • Flipchart • Pens
TEA 10:30 - 11:00	
11:00 – 13:00 Theme 4 Aim 4 Purpose:	Dating <ul style="list-style-type: none"> • To teach caregivers how to increase the skills of women with intellectual disabilities. • To help caregivers to assist the women with intellectual disabilities to be able to differentiate between behaviours that are appropriate and inappropriate in social situations. • To provide caregivers with the necessary skills to teach women about their rights and responsibilities within a friendship or relationship. • To understand the importance of sexuality education for women with intellectual disabilities and the use of social stories in sexuality education.
Process:	<ul style="list-style-type: none"> • Researcher introduces Theme 4 • Ice-breaker: Labelling • Social Story 4: Dating • Activity: Mr and Ms Right • Cool-down activity: Star/Wish?
Material/Equipment:	<ul style="list-style-type: none"> • Reflection and final word • Sexuality and Relationship Training Manual • Measuring instrument • Laptop and Proxima projector • Flipchart • Pens
LUNCH 13:00 - 14:00	
14:00 - 15:00 Conclusion and summary Purpose	To describe the importance of sexuality and relationship education and women with intellectual disabilities and the use of social stories in this type of training.
Process:	<ul style="list-style-type: none"> • Researcher to conclude and summarise the training and sexuality education overall for women with intellectual disabilities. • Social story movie

Slot & Time	Training Session Content
Material/Equipment:	<ul style="list-style-type: none"> • Reflection on training • Sexuality and Relationship Training Manual • Measuring instrument • Laptop and Proxima projector • Flipchart • Pens
15:30 -16:30	Administering post measuring instrument: Experimental and control group

The above table is a summary of the training content. A detailed presentation of the training content is given in Chapter 4.

3.7 SUMMARY

Caregivers are the primary providers of behaviour interventions, specifically where social skills are concerned and when guidance and enforcement of policies and procedures related to sexuality education is required (Kampalan & Li, 2009). Research completed in this area should be used as a basis for policy and procedure development, as well as for the training of caregivers to provide guidance on an ongoing basis for women with intellectual disabilities (Christian et al., 2001). This will ensure that messages conveyed to these women are consistent across all the various caregivers and that the messages are in line with the residential institution's policies and procedures (Kampalan & Li, 2009).

This chapter started by discussing the importance of appropriate policies that need to be in place, and highlights the policy and guidelines for development and implementation as they relate to sexuality and relationship education, staff support and training, and tailor-made programmes. Next, the staff system at one specific residential care facility was explained, and the inclusion of three focus groups to help with the development of the content to be included in a tailor-made sexuality and relationship programme was presented. The aforementioned groups comprised one with residential care facility staff, one with caregivers and one with women with intellectual disabilities. Following the discussion on the development of the training programme in terms of the content, the programme design was described.

Next, the use of social stories as an evidence-based strategy was underscored. The chapter concluded by providing an overview of the proposed training programme.

CHAPTER 4

PHASE 2: The aSeRT Training Manual

4.1 INTRODUCTION

In this chapter, Phase 2, the aSeRT training manual that was developed based on the results from Phase 1 of the research and described in Chapter 3, is provided. This chapter commences with the foreword, which includes a description of the aSeRT followed by a discussion of what the training aims to achieve, the myths and misconceptions about sexuality and a brief overview of the training content and layout of the programme. Thereafter, the four themes (appropriate and inappropriate touching, privacy and appropriate conversations, different types of relationships and romantic relationships) that make up the aSeRT are given. These themes reflect the final changes that were done after the pilot study discussed in Chapter 5. Each of the themes follows the same layout, comparison an introduction, icebreaker, discussion of the aims and outcomes. The keywords, definitions and the resources needed are then described. This is followed by the specific themes, social story, a description of how to read the social story, the activity, a tip, the cool-down activity and finally a reflection and final word. In the last instance, the conclusion and summary of the aSeRT training is provided. Figure 4.1 shows the three different phases of the research, highlighting Phase 2, which is the focus of this chapter. Although Phase 2 dealt with the development of both the aSeRT training and the measuring instrument, only the training manual is described in this chapter, due to the fact that the measuring instrument development changed significantly after the pilot studies, and hence it is discussed in length as part of the quantitative data phase (Chapter 5).

Important note: Please note that the tone used in this chapter differs from the rest of the thesis as it uses simpler language, easier sentence construction and a first person voice.

Every woman with an intellectual disability has the right and need to relate to her own sexuality, the right to privacy and dignity, and the need to express her feelings related to sexuality (Miodrag, 2004). Her right to be free from sexual exploitation and harm is most important. Sexuality encompasses fundamental aspects of who we are as human beings and is an active and inseparable part of reaching our full potential as women. Sexuality and human relationships are physiological needs and a distinct quality of life issue (Richards, Watson, Monger & Rogers, 2011). Definitions of sexuality include concepts such as self-awareness, self-esteem and body image; feelings and emotions, intimacy and relationships, gender and sexual identity (Downs & Craft, 1996). Characteristics of expressing sexuality include having social opportunities and relationships with others. An increasing number of individuals with intellectual disabilities want to know more about their sexuality, are engaging in intimate relationships and requesting appropriate information (Blackburn, 2002; Walker & Harrington, 2002).

4.2.2 What does the aSeRT Aim to Do?

This training aims to help you to support women with intellectual disabilities in addressing appropriate sexuality and relationships by introducing concepts such as appropriate behaviour in public and private places, the ability to differentiate between different types of relationships, appropriate and inappropriate touching, and personal space. The training programme is primarily aimed at women with intellectual disabilities and therefore focuses on the foundation work necessary to teach in sexuality education. In addition, it views sexuality education as an integral part of the life experiences of women with intellectual disabilities. The training programme also attempts to offer ideas to help facilitate sexuality education for women with intellectual disabilities.

The premise of aSeRT is that sexuality education will provide you with an opportunity to equip women with intellectual disabilities with protective behaviours. Adult women with intellectual disabilities may need more education and support because of their increased risk and vulnerability in a variety of situations, including sexual abuse and exploitation. Reasons for increased vulnerability to sexual abuse and exploitation of women with intellectual disabilities include the following:

- Their lack of or limited knowledge with no prior education concerning sexuality issues.
- Their reliance on their sexuality education from non-experts such as their peers, the internet (or cell phones or computers), television and other media resources such as magazines, or a variety of untrained individuals who may or may not have their best interests at heart.
- Their difficulty in retaining information when certain teaching methods are used.

- Their heightened trust in others due to increased dependence on others for assistance.
- Their lack of assertiveness skills and their inability to say “no”.
- Their living arrangements in a sheltered and protective environment, which could be characterised by social isolation.

The importance of empowering you to convey the importance of sexuality education to women with intellectual disabilities and recognising that women with intellectual disabilities are sexual human beings whose needs are more similar to than different to those of the rest of the population, must be taken into account. However, myths generally stem from ignorance, limited experience with women who have intellectual disabilities or narrowly defined views of what sexuality is and the meaning thereof in the lives of individuals with intellectual disabilities. We realise the need for increased information about the sexuality of women with intellectual disabilities, as well as guidance and support, to better understand their sexuality. Women with intellectual disabilities are especially vulnerable to sexual abuse and exploitation and the negative consequences of being in intimate relationships. Our beliefs and values affect how we respond to sexuality issues, especially as caregivers of women with intellectual disabilities. These personal beliefs and values about sexuality could affect how we respond to women with intellectual disabilities and their issues around sexuality. Therefore, it is important to clarify common myths and misconceptions related to sexuality.

Table 4.1: Myths and misconceptions about sexuality and intellectual disability

Myth	Fact
They are asexual (do not have sexual thoughts, feelings or needs) (Milligan & Nuefeldt, 2001).	The need for touch, affection and meaningful relationships are important to all of us (Bernert, 2011).
They are oversexed or uncontrollable (Cuskelly & Bryde, 2007).	Often, a lack of information and reduced opportunities for socialisation contribute to social inappropriateness (Couwenhoven, 2007).
They have increased needs for touch and affection (Johns, 2007).	The need for touch and affection varies as much for these women as it does for all of us. Some individuals enjoy affection while others do not, due to touch sensitivities. Individuals with intellectual disabilities can be indiscriminately affectionate as a result of conditioning, lack of socialisation training or stereotyping (Couwenhoven, 2007).
They experience puberty later than their peers (delayed physical development) (Swango-Wilson, 2008).	Unique patterns of physical development may occur, depending on the individual's health. However, on average, individuals with intellectual disabilities tend to begin puberty at similar ages to their typically developing peers (Couwenhoven, 2007).
They lack the capacity to form lasting relationships (Forchuck et al., 1995). They are sterile (Couwenhoven, 2007).	More and more women with intellectual disabilities are achieving this goal (Bernert, 2011). There is reduced fertility in both males and females, but incidences of reproduction for males and females have been documented (Couwenhoven, 2007).
They are not capable of taking responsibility relating to a marriage (Phasha, 2009).	Many individuals with intellectual disabilities get married, but there is little information on long-term outcomes of these marriages. Statistics on successful marriages are expected to be similar to those of successful marriages in the general population (Bernert, 2011).

4.2.3 What Exactly Can I achieve by Attending this Training?

Working through the training programme should help you develop both your knowledge and skills regarding sexuality and relationship education for women with intellectual disabilities. Individual application of the learning will vary, and the programme might not always give you all the answers. You are expected to develop sensitivity to issues related to sexuality and relationships that will equip you to work more effectively.

4.2.4 What does the aSeRT Offer?

There are four themes in this programme. Each theme is briefly described in the table below, in other words, what the main focus of the theme would be, as well as the aim, the social story and the activity. A brief bird's eye view of what the programme offers is shown in Table 4.2.

Table 4.2: Brief overview of training programme content

Introduction of training					
The purpose of sexuality and relationship training and the specific aims are addressed.					
Training method					
The methods, activities and stories to equip women with intellectual disabilities with social skills related to sexuality and relationships are explained and demonstrated.					
Theme	Aim	Social story	Icebreaker	Activity	Cool down activity
Appropriate and inappropriate touching	To teach social boundaries	All about hugs	Greetings permission game	Piece of string	Big fish, small fish
Privacy and confidentiality	To understand the concept of being discreet	Happy and unhappy secrets	Activity of sorting cards of happy and unhappy secrets	Dare to share	Exercise of "Private talk"
Different types of relationships	To discuss different types of relationships	Relationship circles	Attraction	Social boundary circle chart	"Phone a friend"
Romantic relationships	To discuss romantic relationships	How are relationships similar and how are they different?	Labelling	Experiential learning: what have you learned?	Group puzzle: photograph
Conclusion and summary	To discuss the importance of supporting sexuality education	No social story	No icebreaker	No activity	Reflection on training

Each theme starts with an **icebreaker**. What does this mean? The term "icebreaker" is derived from "breaking the ice", which, in turn, is derived from special ships called "icebreakers", which are designed to break up ice in the Arctic and Antarctic regions. Ice-breaker ships make it easier for the ships to travel and similarly the "ice-breaker" activity helps to clear the way for learning to take place

by making everyone more comfortable and to encourage conversation. The idea of the “icebreaker” is therefore to create a warm, friendly, personal environment, as this creates better participation opportunities enabling you to learn more. In addition, the challenge is to stretch your time to form positive relationships and a strong learning community, and to promote important 21st century skills such as communication, problem-solving and empathy. All of this along with the requirements of covering the required training curriculum.

The **social story** follows. Social stories are short and typically written with the aim to describe a behaviour (for example, hugging) and the anticipated behaviour associated with each (for example, who to hug, and when to hug). Social stories also provide social information to teach appropriate (versus inappropriate) social behaviour by making some of the unwritten and unspoken rules, as well as non-verbal cues, more obvious (for example, arms folded across the chest means “I do not want a hug”). Social stories can therefore serve the purpose of introducing and changing behaviour. A specific social story was written for each of the four themes of the aSeRT programme. The social stories were developed in a book form, using pictures that are easy to understand and short sentences to make the stories clearer. The written social stories inform or describe an activity and the expected behaviour associated with it. Three types of sentences are included for all the social stories in this programme, namely:

- i. A descriptive sentence that describes where the situation occurs, who is involved, what they are doing and why;
- ii. A perspective sentence that describes the reactions and feelings of the individual and of the other people; and
- iii. A directive sentence which tells the individual what to do (Gray, 2003).

Next, a specific **activity** is included, followed by a **cool-down activity**, which aims to end the session in a relaxing and fun way. Activities were chosen to facilitate sexuality training and education in a way that is appropriate for women with intellectual disabilities.

Finally, each theme ends with a **reflection and final word**. Reflection involves describing, analysing and evaluating your thoughts, assumptions, beliefs and actions (Alsop & Ryan, 1996). It includes three important components that will help you make the most of the training, as follows:

- *Looking forward* (prospective reflection): That is like looking at a holiday brochure before you go away. You get ideas about what the destination location might be like, what you might like to do and who you might meet.
- *Looking at what you are doing now* (perspective reflection): That is like looking at yourself in a mirror or in a pool of water. It shows you as you are at that point in time.
- *Looking back* (retrospective reflection): That is like looking at the photographs or the videos when you come back from a holiday. It reminds you about where you went, what you did and who you met.

4.2.5 What Icons Will Point You to Core Information?



Introduction



Icebreaker



Aims



Outcomes



Keywords and definitions



Resources needed



Social story



How to read a social story



Activity



Tip



Cool-down activity



Reflection and final word

4.3 Theme 1: Appropriate And Inappropriate Touch

i Introduction

Touch is essential to human life. Often, the rules for touch and affection are unclear or they may change, based on culture and context. Putting an arm around a close friend is usually acceptable, but unacceptable with someone you meet for the first time. Thinking about touch within certain contexts and situations can help us with what information women with intellectual disabilities may need to help them develop and improve their understanding of appropriate and inappropriate touching. Individuals with intellectual disabilities are less likely to pick up non-verbal behaviour from other people and usually require direct instruction and verbal feedback. There are times when touch and affection look out of place because the behaviour does not match what other people would expect from a person without a disability of the same age. People with disabilities need to be taught how to adopt a set of concrete and conservative rules by teaching them greetings that are socially appropriate to use with authority figures. For example, handshakes, head nods, smiles and verbal greetings are appropriate ways to greet authority figures such as caregivers, the director of the residential care facility or the nurse.



Icebreaker: Greetings permission game

This game aims to relax the group, practice turn-taking skills and talking and listening to each other.

Chat with a friend



Aim

Teach social boundaries and reinforce healthy boundaries in relationships which involve knowing the rules for how interactions occur in different situations.



Outcomes

After completing this module you should be able to:

- understand that women with intellectual disabilities have the right to give permission to who touches their bodies;
 - know how to teach these women about appropriate and inappropriate touch that will empower them with the skill of ownership;
 - teach these women how to respect personal boundaries;
 - teach these women how to ask permission to move into someone else's personal space;
 - teach these women how to create an awareness of appropriate greeting styles, such as hugging, shaking hands or giving a high five.
- i. Ask the participants to turn to the person sitting next to them so that all persons will be working in pairs.
 - ii. Let the participants tell their partners something about themselves, such as their favourite food or favourite hobby.
 - iii. Each person then tells the rest of the group what her partner has told her, but first making sure that she has permission to do so!



Keywords and definitions

Affection: A feeling of desire towards another person.

Attraction: When two adults are attracted to each other, they want to be close and feel excited and happy when they are together.

Feelings: If appropriate touch is involved, a positive feeling will be felt by both parties.

Permission: When you and your partner agree to be together in a healthy relationship.

Touch: When you know the rules for appropriate and inappropriate touch.







Resources needed

A piece of string.



Social story 1: All about hugs

 <p>All about hugs</p> <p>Appropriate and inappropriate touching</p>	 <p>Hugs feel good</p>	 <p>Hugs are a way to show love</p>	 <p>Hugs are a way to show concern</p>
 <p>Hugs make us feel happy!</p>	 <p>Is it ok to hug anyone when I feel like it?</p>	 <p>What is the rule?</p>	 <p>The rule is NO! I must ask first!</p>
 <p>Ask: "Can I give you a hug please?"</p>	 <p>Wait for the answer "YES" or "NO"</p>	 <p>It is ok to hug Mom or Dad</p>	 <p>Is it ok to hug anyone in public that I am not attracted to or don't trust?</p>
 <p>No hugging strangers in public</p>	 <p>I do not hug the caregivers</p>	 <p>I respect personal space</p>	 <p>I can wave or say hi</p>
 <p>I can high five!</p>	 <p>I CAN shake hands</p>	 <p>Good! Now I know what to do!</p>	



How to read a social story

You will read the social story with the individual and point to the pictures. You might have to re-read the story several times. Each individual will receive her own book and should be encouraged to "read" the book as often as she wants to. For some women this may mean reading the words, while for others it may mean looking at the pictures. If the individual is unable to read, the story can be recorded and the individual can be taught to use a recorder and to turn the page when prompted by

an auditory signal. Remember: participation depends on each woman's own needs and abilities.



Activity

Have one woman stand in the middle of a circle shaped by piece of string and then tell her the following:

- Your body is your own and you can decide who you want to share it with.
- Sharing your body can mean different things: giving someone a hand, sitting on another person's lap, hugging or touching somebody else.
- You decide what feels okay for you.
- Nobody can force you to share your body if you do not want to.
- You can say "stop", or "I don't like it", or "it's my body", or "don't touch!"



Tip

When you talk about the social story or the activity, reinforce keywords and themes.



Cool-down activity

I Swim.

Divide the group into smaller groups of five each. This activity is called "big fish, small fish". The leader of the group will ask the women to hold their own hands together. When you instruct them by saying "big fish", they will indicate "big" by demonstrating it by separating their hands, when you instruct "small fish", they will demonstrate "small" by bringing their hands together. You will observe the first person who is hesitant and she will be eliminated. The game will continue until one person is left in the group, who will win a prize.



Reflection and final word

Make time for the group to remember and reflect on what they did in the session and reflect on what they learned in the session, including what they enjoyed most or did not enjoy.

If you struggle to decide what type of touch and affection to teach, try and think of doing the behaviour in a public place, such as a shopping mall or coffee shop. Think about how strangers would view the

behaviour. How would family members or friends view this behaviour? How do you view this behaviour?

Think about the long-term implications of what is appropriate and remember that sexuality education needs to be reinforced on an ongoing basis. Changing an existing appropriate behaviour is more difficult than teaching a new behaviour. Remember, as a caregiver you may already be familiar with terms that women with intellectual disabilities understand. If you are unsure, ask if they understand the meaning of the words you are using. The easiest and more basic explanations are the most effective ones. As you introduce new vocabulary or concepts, make sure that the women understand them. Ask questions or use the pictures of the social story to evaluate learning. Repeat, review and reinforce the social stories, because once-off reading of the story does not work for individuals who have an intellectual disability.

4.4 Theme 2: Private Talk And Appropriate Conversations

i Introduction

Almost every topic under the umbrella of sexuality involves an understanding of public versus private concepts. This is seen in concepts like private and public body parts (for example, arms) and private body parts (for example, female breasts); public places (for example, shopping malls) and private places (for example a bedroom), and also in terms of public conversation topics (for example, friendship) and private conversation topics (for example, sex). Women with intellectual disabilities often have difficulty being tactful and understanding the boundaries between private and public, which is an important component of social appropriateness (Couwenhoven, 2007). For example, a young woman with an intellectual disability, excited about getting a new lace bra with pretty flowers, may want to tell and possibly also show everyone at a family get-together. Helping women with intellectual disabilities to be tactful is often a necessary component of sexuality and relationship education. Once the understanding of “privacy” and “confidentiality” or so-called “appropriate conversations” or “private talk” is understood, the labelling of specific topics during conversations as either private (inappropriate for discussing with strangers) or public (can talk about this with others) will enhance the women with intellectual disabilities’ ability to be socially appropriate when having conversations with others. In addition, women with intellectual disability often have difficulty with the concept of being tactful related to other issues beyond sexuality (Couwenhoven, 2007). For example, they may ask adults their age, how much money they have, or share details about medical conditions that are usually considered private. Labelling new information with the women with intellectual disabilities as private can help

prevent social mistakes and protect them from exploitation. For example, not all people are comfortable talking about sexuality issues in public places when others are around. Furthermore, the concept of “secrets” is confusing for individuals with intellectual disabilities. They need to be taught to differentiate between some secrets (so called “happy secrets”) which are appropriate, for example a surprise birthday party. Some secrets which are harmful, especially if they stop someone from getting the help they need, are called “unhappy secrets”.



Icebreaker: Activity cards of “happy” and “unhappy” secrets

- Use a piece of A5 cardboard cut in half, with the statements that follow written separately on each of them.
- Ask participants to sort them under correct categories, “happy” or “unhappy” secrets.
- The cards should be presented in random order.
- *Happy secrets:*

I'm arranging a birthday party for Carla on Friday. Don't tell her, it's a secret surprise. I think this will make her very happy.

I like that new guy who has just come to stay in the residence. Please don't tell him. I want to get to know him better.

Look, this is a present for Mpho. Don't tell her what it is because it's a secret.

Mary's aunt is coming to visit. She doesn't know. We shouldn't tell her. It's a secret.

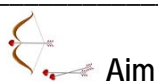
- *Unhappy secrets:*

My uncle likes to kiss me and touch my private parts. He says I mustn't tell anyone because it's our secret.

If you take your clothes off for me I'll give you a box of chocolates, but then you're not allowed to tell anyone.

My brother's friend likes it when I touch him under his clothes when we are alone. He says I mustn't touch him when others are around. It's a secret.

My boyfriend hits me. He says it's because I make him angry. I mustn't tell anyone. It's our secret.



Understand that being tactful is an important component of behaving socially appropriate and having appropriate conversations. By teaching these concepts, women with intellectual disabilities can learn to act more appropriately within social contexts, and they can also be protected from exploitation.

≡ Outcomes

After completing this module you should be able to:

- understand the difference between “happy” secrets and “unhappy” secrets;
 - know the difference between privacy and confidentiality;
 - create an awareness of being discreet in the presence of others;
 - know how to label new information as private or public.
-



Keywords and definitions

Privacy: to be private without being disturbed

Confidentiality: when private information is shared with others who are not supposed to share the information with anyone else.

Tactful: to be sensitive to what you say in the presence of others.

Secret: to keep something to yourself and not tell others. There are happy and unhappy secrets.

Happy secrets: when you want to make somebody happy by keeping from them a secret such as a birthday party, which will make them happy.

Unhappy secrets: when people want to take advantage of you and ask you to keep secrets about the sexual things they do.

Consent: to give permission for something to be done.

Bribe: when a person gives you gifts, money, treats or special time together to persuade you to do something you don't want to. Someone might bribe you to get you to do sexual things with them.

Threat: A threat means that a person will try to scare you into something you don't want to do. For example, normally you might say “no” but you are too afraid.



Resources needed

Scissors

A5 cardboard cut in half

Wigs

Hats



Social story 2: Happy and unhappy secrets

<p>Happy and Unhappy secrets</p>  <p>Happy secrets do not hurt anybody!</p>	<p>Happy secret</p>  <p>It means you can tell somebody right away.</p>	 <p>We arranging a birthday party for Mpho. We can't tell her now, because it is a secret!</p>
<p>She will find out later!</p>  <p>Surprise!!!</p>	<p>Are all secrets happy?</p>  <p>No, some secrets make us feel unhappy!</p>	<p>Why?</p>  <p>They can make you do things you don't want to do!</p>
<p>They can bribe you:</p>  <p>for example, a person can give you gift money or treats or special time together to force you to do something you don't want to do!</p>	<p>They can threaten you:</p>  <p>For example, normally you might say "no" but you are too afraid. The person will try to scare you into something you don't want to do.</p>	<p>What can you do if a secret makes you unhappy?</p>  <p>Run! Yell! Tell!</p>



How to read a social story

You will read the social story together with the individual and point to the pictures. You might have to re-read the story a few times. Each individual will receive her own book, and should be encouraged to "read" the book as often as she wants to. For some women this may mean reading the words, while for others it might mean looking at the pictures. If the individual is unable to read, the story can be recorded and the individual can be taught to use a recorder and to turn the page when prompted by an auditory signal. Remember that participation depends on each woman's own needs and abilities.



Activity

Dare to share: Ask women if they are brave enough to share the answers to these questions with the rest of the group.

- Who is your favourite singer?
 - Do you sometimes eat your dessert before your food?
 - What is your favourite programme on television?
 - Who is your role model?
 - Do you snore?
 - Do you sing in the bath?
 - Do you talk to yourself?
-



Tip

When you discuss the social story or the activity, reinforce keywords and themes.



Cool-down activity

I Swim.

Tell the group that they are going to role-play but not as themselves. Encourage participants to think of names for their characters to help them to depersonalise themes. Assist the group to not personally identify with doing something bad or feeling angry. Pair each participant with another participant, and tell them that they are going to do something about saying "no". Each participant can choose from several items (wigs and hats) that they think will portray their character. Give time to practise the scenes and be aware that they may need to help. Give some direction if needed. Set up acting space. Ask the group to introduce each of their characters. Create an imaginary scene where everything takes place. For example, participants can role-play two friends, the one addicted to drugs, offering the other participant to use drugs with her and she has to say "No!" Another example is where two participants can role-play mother and daughter. The mother tries to force her daughter to have an abortion and the daughter says "No!" Discuss what happened in each scene afterwards.



Reflection and final word

Make time for the group to remember and reflect on what they did in the session and reflect on what they learned in the session, including what they enjoyed most or did not enjoy.

To be able to help women with intellectual disabilities to learn how to be tactful, it is often necessary to enhance their understanding of the concepts public and private, labelling specific topics as either





private (in other words, inappropriate for discussing with strangers) or public (in other words, appropriate to discuss with others) thereby enhancing their ability to be socially appropriate. Labelling new information you are sharing with the women as “private” can help them to prevent social mistakes and also protect them from exploitation and others taking advantage of them. Teach them a visual cue that signals that a subject is considered private. For example, lowering your voice, putting a hand up, placing a finger on closed lips or making a zipping action of a closed mouth, could help them to know and remember that the subject is off limits for this situation. Remind them that not all people are comfortable talking about sexuality issues in public places when others are around. Teach women about private conversations by indicating to them in different situations and different contexts that the conversation should be done in a private or public place.





4.5 Theme 3: Different Types Of Relationships

i Introduction

When teaching women with intellectual disabilities how relationships are similar or different, it is important to explain the following concepts related to different types of relationships to them. The different types of relationships are represented by different circles as shown in Table 4.3.

Table 4.3: Different types of relationships

Relationship category	Description	What role does this person play in your life?	What type of touch is appropriate and what is not appropriate?
Circle 1: Inner circle 	That is you.	You are in charge of yourself.	You can also decide how you want to be touched.
Circle 2: Family members 	People who provide love and support. People you love and trust.	Provides food. Provides a place to live. Provides medical care. Provides love.	A wide range of different types of touching, but no sexual touching
Circle 3: Friends 	Someone who has similar interests. Someone who you enjoy being with and who enjoys being with you. Someone who stands up for you. Someone who respects you. Someone who is honest. Someone who keeps promises.	Shares hobbies and interests. Goes places with you. Talks to you and hangs out with you.	Similar to what same-age friends use. No sexual touching.
Circle 4: Romantic partners 	Someone you have sexual feelings for. Someone who has sexual feelings for you.	Shares hobbies and interests. Goes places together. Talks and hangs out together. Touches you and shows	Varying levels of affection. Intimate touching with permission.

Relationship category	Description	What role does this person play in your life?	What type of touch is appropriate and what is not appropriate?
	Someone you are dating. Not everyone has a sweetheart.	affection. Shares special moments and expresses intimacy.	
Circle 5: Caregivers 	Someone who is paid to help you or to assist you.	Supports you in specific ways. Teaches you. Takes care of you. Makes sure you are healthy (nurse). Takes you to the mall (driver). Helps you do your job better (job coach). Teaches you how to play a sport (coach).	Verbal greeting. Limited touching. No sexual touching.
Circle 6: Community helpers: policemen, doctors, security guards 	People who are paid to help others (not only you).	Supports others (not only you) in specific ways. Keeps people in the community safe. Transports people (bus driver). Helps you find things, for example, at Pick n Pay (the clerk).	Verbal greetings.
Circle 7: Neighbours 	People you know in the neighbourhood.	People you are familiar with in the neighbourhood.	Verbal greetings.
Circle 8: Strangers: 	Strangers are new people you see everywhere, and you do not know them.	People you do not know.	No touching.

Teach women about different types of relationships that involve knowing certain rules on how to interact and behave appropriately in different social situations. Interpreting verbal and non-verbal cues from others can sometimes be difficult for these women as they generally have fewer opportunities to generalise skills to real-life settings. You will help them by giving them some control by asking the adults involved in their lives to first ask permission before touching them, or by applying the same rules they use when interacting with typically developing adults.



Icebreaker: Attraction

- Show how magnets stick together.
- This sticking together is called "attraction".
- Let the group experiment with the magnets and discover what the magnets are attracted to, such as paperclips, chair legs, money, etcetera.
- People can also be attracted to each other.

- When two people are attracted to each other they want to be close to each other and feel excited and happy when they are together.
 - Show a picture of a couple kissing to illustrate the discussion.
 - Stress that this sort of attraction is for teenagers and adults and not for children.
 - Place pictures of individual people on the floor, including a selection of age groups.
 - Ask which people might feel attracted to each other.
 - Attraction in a loving sexual relationship needs to be mutual – both people must feel attracted to each other.
-



Aim

Explain the difference between a loving relationship and a relationship between family and friends.



Outcomes

After completing this module you should be able to:

- teach women about specific characteristics that make relationships healthy or unhealthy;
 - know how to improve the decision-making of women with intellectual disabilities in how and when to continue or to end a relationship;
 - understand different types of relationships; and
 - discuss specific characteristics that make relationships healthy or unhealthy.
-



Keywords and definitions

Caregiver: is someone who is paid to assist you.

Community helpers: are people who are paid to help you and others.

Family: are people who provide love and support and are people who you can trust.

Friends: are people who have similar interests to you and who you enjoy being with.

Neighbours: are people you know in the neighbourhood.

Romantic partner: is someone who you are attracted to and who is attracted to you.

Strangers: are new people you see everywhere, and who you do not know.



Resources needed

Eight cardboard circles that show different categories of relationships.

Pictures from magazines and newspapers showing different relationships' personal photos.

Social boundary circle chart.

A cell phone or an old phone



Social story 3: Relationship sequencing

<p>Relationship sequencing</p> <p>My relationship circles</p>	<p>Circle 1</p> <p>My inner circle, that is me. I am in charge of myself. I must take ownership of who is allowed to touch me appropriately and who is not.</p>	<p>Circle 2</p> <p>My family is people who love and support me and who I can love and trust.</p>
<p>Circle 3</p> <p>Friends are people who have similar interests than I do. I enjoy being with them and they enjoy being with me. My friends respect me and I honest with me. They keep their promises.</p>	<p>Circle 4</p> <p>When I am in a romantic relationship, I have sexual feelings for the other person and the other person has sexual feelings for me. When I am in a romantic relationship it is usually someone I am dating.</p>	<p>Circle 5</p> <p>Caregivers are people who get paid to assist me!</p>
<p>Circle 6</p> <p>Community helpers are people who get paid to help others such as policemen!</p>	<p>Circle 7</p> <p>Neighbors are people I know and are familiar with in the neighborhood!</p>	<p>Circle 8</p> <p>Strangers are new people I see everywhere. I do not know them!</p>



How to read a social story

You will read the social story with the individual and point to the pictures. You might have to re-read the story a few times. Each individual will receive her own book, and should be encouraged to “read” the book as often as she wants to. For some women this may mean reading the words, while for others it may mean looking at the pictures. If the individual is unable to read, the story can be recorded, and the individual can be taught to use a recorder and to turn the page when prompted by an auditory signal. Remember participation depends on each woman’s own needs and abilities.



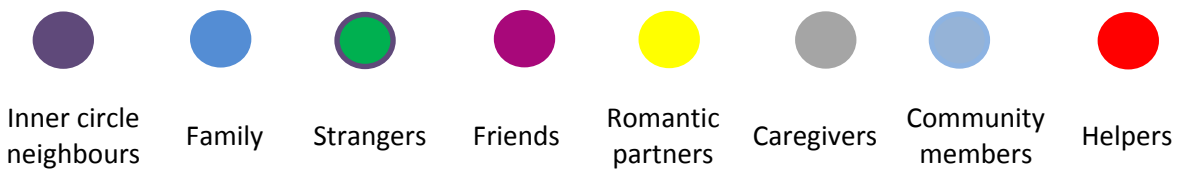
Activity

Ask the women to discuss which people in their lives are most important. Emphasise that these are the ones they love and trust.

The name, photo or drawing of each person can be written or stuck inside every specific circle.

Explain that each circle represents a relationship category of the person or people they love and trust and can be stuck in the specific circle (demonstrate).

The coloured cardboard can be replaced, having the women draw their own coloured circles on plain white paper.



Tip

- *When you talk about the social story or the activity, reinforce keywords and themes.*
- *If you do not have the resources available above, you can replace them with a whiteboard or white A3 paper on which you can draw six different colours of circles that represent different relationship categories*
- *Pictures from magazines can also be used if personal photographs are not available.*



Cool-down activity

I Swim.

Place a phone in the circle and pretend that it is ringing. Someone will answer the phone and pretend that she is having a conversation. All the others must guess what the relationship is by how she is talking and her body language. Examples such as a stranger phoning or a family member can be role-played.



Reflection and final word

Make time for the group to remember and reflect on what they did in the session and reflect on what they learned in the session, including what they enjoyed most or did not enjoy.

To help the women with intellectual disabilities learn, it is important that you help them understand why it is important that they know the different types of relationships and how they should interact with different people, as well as what behaviour is appropriate or not appropriate. In addition, you need not only tell them what you want them to do, but also show them what they should know. Emphasise the importance of repeating it several times, as repeated instruction has real benefits for everybody.

4.6 Theme 4: Romantic Relationships

i Introduction

Have you ever had a crush on someone? Have you ever felt that tingly excitement of love at first sight or enjoyed the first moments of a new romantic relationship? Then you will know the meaning of *attraction*. People are attracted to those with whom they can have a rewarding relationship. When it happens, does it feel good to be with that person who has the same interests as you? Can you think of one person who you trust? Why do you trust that person? Is that person kind to you? Does that person listen when you talk? Does that person help you? Characteristics such as honesty, affection, helpfulness, a willingness to listen and compromise, enjoying time spent together and showing shared interests impact a relationship. Romantic relationships mean two people having sexual feelings for each other. Sometimes you are attracted to people you know; other times you might be attracted to people you do not know. There are people you cannot be romantically involved with, for example a family member or a caregiver. Dating is a planned activity that can assist in decision-making regarding healthy or unhealthy relationships. Both partners have to show a need for dating each other. If the person you like does not show any interest, you have to let go. If you are not interested in somebody else, you can say no. Women with intellectual disabilities should be reminded that they may speak to you as their caregiver when they feel ready to date. It is important that values, criteria and the natural progression of dating are then addressed. Teaching women how to start conversations can help them meet new people and feel more comfortable in new social situations. When they understand how to be more assertive, others will be less likely to take advantage of them, resulting in greater freedom and independence. Teaching women ways to start conversations can also help them improve their social decision-making skills.



Icebreaker: Labelling

- Each person gets a label, chooses her favourite animal and writes the name of the animal on the label.
- Stick the label on the forehead of the person in front of you without the person knowing what is written on the label.
- You need to act out the animal's behaviour for the person to guess which animal is your favourite animal.



Aim

Teaching about boundaries in romantic relationships to help women with decision-making about what is healthy and appropriate in different types of relationships.

= Outcomes

After completing this module you should be able to:

- name the romantic relationship rules;
- describe how to interact in a socially acceptable manner;
- realise how relationships are similar or different; and
- understand boundaries in relationships and appropriate touch.



Keywords and definitions

Romantic relationship: when two people are attracted to one another in a sexual way and have the same interests.

Appropriate date: when you and the other person are both willing to learn more about each other and want to spend time together, and then decide if you are a good match.


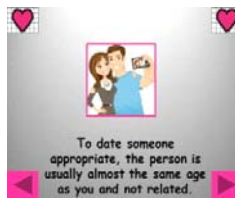





Resources needed

Pen and paper



Social story 4: A Romantic Relationship

 <p>A Romantic Relationship</p> <p>Having a romantic relationship can be really fun!</p>	 <p>Getting presents is fun and exciting too!</p>	 <p>It is exciting to be with someone really special.</p>	 <p>But it is important that the person who is spoiling you is the right person!</p>
 <p>How do you find this out?</p>	 <p>When two people plan a date it is an activity that both agree upon and that both will enjoy doing!</p>	 <p>To date someone appropriate, the person is usually almost the same age as you and not related.</p>	 <p>The person you are interested in is someone who is available to be in a relationship and not already dating someone or married.</p>
 <p>Unsafe places are called red light places.</p>	 <p>There are safe and unsafe places to meet new people. Safe places to meet people are called green light places.</p>	 <p>Green light places to meet people are places such as church, the group home, social groups or friends of friends.</p>	 <p>When having a romantic relationship with someone else, that person is interested in getting to know you better and has almost the same interests and abilities that you.</p>
 <p>It feels comfortable to be with someone who you are romantically in love with and who understands what it is like to have a disability.</p>	 <p>Both you and the person you ask have to want to be in a romantic relationship with each other.</p>	 <p>If the person is not interested, he can say no.</p>	 <p>If you are not interested, you can say no.</p>



How to read a social story

You will read the social story with the individual and point to the pictures. You might have to re-read the story a few times. Each individual will receive her own book, and should be encouraged to "read" the book as often as she wants. For some women this may mean reading the words, while for others it may mean looking at the pictures. If the individual is unable to read, the story can be recorded, and the individual can be taught to use a recorder and to turn the page when prompted by an auditory signal. Remember that participation depends on each woman's own needs and abilities.



Activity

Have the group build a puzzle of a group photo taken to enhance the understanding and collaboration of teamwork within the residential care facility.



Tip

When you talk about the social story or the activity, reinforce keywords and themes.



Cool-down activity

I Swim.

Have each participant reflect on what they learned during the training by asking them questions and sharing it with the group. For example:

- What have you learned about yourself during the training?
 - If you could giving a star to anybody, who would you give it to and why would it you give it?
 - If you could grant anybody a wish, who would you grant it to on their journey from here?
-



Reflection and final word

Make time for the group to remember and reflect on what they did in the session and reflect on what they learned in the session, including what they enjoyed most or did not enjoy. Knowing how to answer the following questions will help you to enhance women with intellectual disabilities' social decision-making skills to become more assertive within romantic relationships:

- What is the difference between other relationships and romantic relationship?
- What is the correct way to behave in a romantic relationship?
- What is acceptable behaviour for a man in a romantic relationship?
- What is acceptable behaviour for a woman in a romantic relationship?
- What is allowed in a romantic relationship?
- What is not allowed in a romantic relationship?

4.7 CONCLUSIONS

Sexuality can be defined as the quality or state of being sexual. Very often it is an aspect of one's need for closeness, caring and touch. People's understanding of their sexuality is central to their self-

image and self-awareness, and impacts greatly on how they relate to themselves and others. An individual's sexuality and sexual behaviour should be viewed in the context of overall personal and social development, knowledge and skills. Sexuality and relationship education for women with intellectual disabilities has a strong protective focus and attempts to teach women with intellectual disabilities about the following:

- appropriate and inappropriate touching;
- privacy and appropriate conversations;
- different types of relationships; and
- romantic relationships.

It is important to teach individuals with intellectual disabilities what a positive relationship can be in order for them to understand unhappy “red light” relationships. The main aim of the training is to provide support and inform them to make healthy choices. Finding the right words to explain sexuality concepts is challenging, as we have a natural tendency to use complex words and go into more detail than is necessary.

You have the best opportunities to teach women with intellectual disabilities about what constitutes appropriate and inappropriate touching, privacy and appropriate conversations, relationship sequencing, romantic relationships and other social skills. Therefore, we want to empower you with the knowledge on sexuality issues to be able to educate women with intellectual disabilities.



Keywords and definitions

Communication: A verbal action taking place between a sender and a receiver.

Consent: Giving someone permission.

Educate: Giving person information to improve knowledge to their benefit.

Empower: Giving another person confidence.

Rights: Things that are morally good or justified.

Sharing information: Learning skills through experiential learning.

Social skills: Techniques learned through a precise set of instructions in a written manual.

Needs: Things that improve the well-being of an individual.

Values: Patterns of behaviour with a particular culture.



Tip

Learning opportunities that engage the senses are more likely to improve understanding. To make abstract sexuality concepts more concrete, use slides, demonstrate or show a movie clip. In addition, use simple, easy-to-understand language. You may already be familiar with terms that women with intellectual disabilities understand. If you are unsure, ask such a woman if she understands the meaning of the words you are using. The simplest and most basic explanations are most effective.

When you talk about the social story or the activity, reinforce keywords and themes.



Reflection on training

Make time for the group to remember and reflect on what they did in the training and reflect on what they learned in the social stories and activities, including what they enjoyed most or did not enjoy.

This sexuality and relationship education training programme has provided you with the following knowledge:

- How to provide women with intellectual disabilities with social skills.
- How to differentiate between behaviours that are appropriate in social situations, as opposed to those seen in the media.
- How to understand rights and responsibilities within friendships and relationships.
- How to facilitate sexuality education of adult women with intellectual disabilities.
- How to recognise sexuality as a healthy and positive aspect of being human.
- How to share information.
- How to explain the value of communication.
- How to use social stories in sexuality education.
- How to be effective in a group.

Rebecca Johns (2005) suggests that sexuality education is an issue that many parents, caregivers and teachers find difficult to talk about, which makes it difficult for them to assist and guide women with intellectual disabilities about their sexuality. Unfortunately, most individuals with disabilities learn about their sexuality through the media, friends or sexual experimentation and even technology, rather than through appropriate adult guidance. As previously said, sexuality includes physical, ethical, spiritual, psychological and emotional dimensions. Every woman with or without an intellectual

disability has dignity and self-worth. Individuals express their sexuality in various ways. We need to respect and accept the diversity of values and beliefs about sexuality that exist in all communities. Relationships should never be exploitive or coercive. All decisions related to sexuality have effects and consequences. All women, including women with intellectual disabilities, have the right to education to enable and empower them to make responsible choices.

4.8 SUMMARY

In this chapter the content of the custom-design aSeRT training manual that was developed in Phase 2 of the research was described. The four themes developed and identified provided a basis on which the training was developed, specifically for training in certain areas of sexuality education for caregivers.

CHAPTER 5

Phase 3: Quantitative phase

5.1 INTRODUCTION

In this chapter, the research methodology used in the third phase of the research, the quantitative phase, is discussed. Firstly, the aims (including the main aim and sub-aims) are described, followed by a discussion of the research design. The development of the materials, specifically the measuring instrument, is then explained, followed by an in-depth discussing of the pilot study focusing on the objectives and procedures, with its results and recommendations for the main study. Finally, a description of the participants, the data collection procedures, the material and equipment used in the main study, as well as data analysis, follow.

5.2 AIMS

5.2.1 Main Research Aim

The main aim of this study is to describe the effect of a two-day, custom-designed sexuality and relationship education training programme, aSeRT (a Sexuality and Relationship Training Programme) on the attitudes and knowledge of caregivers of women with intellectual disabilities. The material centres on the sexuality of the women under these caregivers' charge, and makes use of social stories to convey the key messages.

5.2.2 Sub-aims

The following five sub-aims were formulated to attain the main aim:

- i) To collect qualitative data (via three focus groups) to enable the development of a sexuality and relationship education training programme custom designed for women with intellectual disabilities, namely the aSeRT. (This sub-aim was addressed in Phase 1 and described in Chapter 3 and Chapter 4).
- ii) To implement the two-day, custom-designed, aSeRT programme with caregivers of women with intellectual disabilities to address sexuality related aspects extrapolated from Phase 1 of the research, namely appropriate and inappropriate touching, privacy and appropriate conversations, romantic relationships and different types of relationships.

- iii) To measure the attitudes and knowledge of caregivers of women with intellectual disabilities, regarding sexuality and relationships, related to the aspects described in sub-aim ii before and after training, by means of the measuring instrument
- iv) To describe caregivers' evaluation of the custom-designed aSeRT training and their satisfaction with the programme.
- v) To compare the pre-test and post-test measures in order to describe the effect of implementing the aSeRT programme.

5.3 RESEARCH DESIGN AND PHASES

This study included three main phases. Phase 1 focused on the qualitative data and the programme design considerations. Phase 2 focused on the development of the aSeRT training programme. Phase 3 was quantitative in nature, and focused on the implementation of the aSeRT. Phase 3 commenced with three distinct pilot studies. Figure 5.1 outlines all the research phases but highlights Phase 3, which is the focus of this chapter.

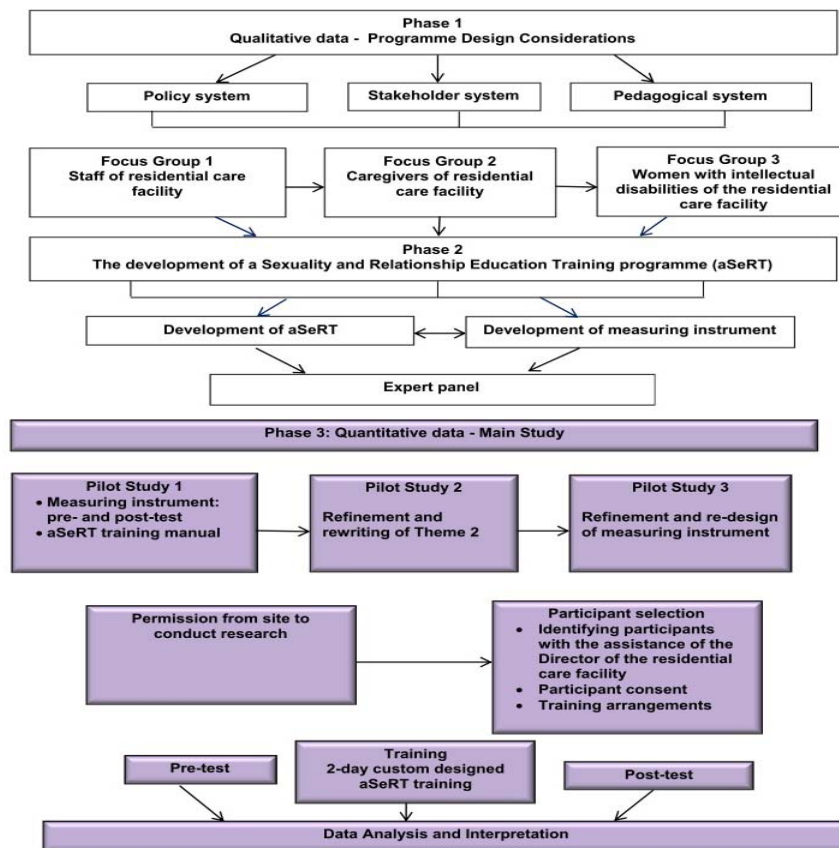


Figure 5.1: Schematic outline of the three research phases: Phase 3

A sequential exploratory mixed methods research design was used as it most accurately addressed the main aim of the research. This design involves a first phase of qualitative data collection and analysis, followed by a next phase of quantitative data collection and analysis that builds on the results of the first qualitative phase (Creswell, 2012). The primary focus of this design is to initially explore a phenomenon, namely the attitudes and knowledge of caregivers related to the sexuality of women with intellectual disability in their care. Using this three-phase approach, the researcher first collected qualitative data (Phase 1) and analysed it in order to develop a training programme (Phase 2) that was subsequently administered to a sample of a population (Phase 3). The advantage of this design is its specific approach (qualitative research followed by quantitative research), which makes it easy to implement and straightforward to describe and report on (Creswell, 2012). Furthermore, it lends itself to the development of new materials, such as the custom-designed sexuality and relationship training programme of this study. The sequential exploratory mixed method design does, however, require a substantial length of time to complete the different data collection phases, which can be a drawback for some research situations (Creswell, 2013). Finally, key decisions need to be made about which findings from the initial qualitative phase will be focused on in the subsequent quantitative phase, for example, which specific themes will be included in the training programme (Creswell, 2012).

5.4 MATERIALS

The aSeRT developed for this study uses four custom-designed sets of material, namely the training manual, the training pack, the measuring instrument, and the training evaluation questionnaire. Each of these will be described in more detail.

5.4.1 Training Manual

The development of the aSeRT was described in detail in Chapter 3 and constituted the qualitative phase of the study. A complete example of the aSeRT training manual is provided in Chapter 4.

5.4.2 Training Pack

A training pack was compiled to cater for all components of the training, namely icebreakers, activities and cool-down activities included in each theme of the training programme. Each training pack included: a piece

of string, a pair of scissors, a magnet, a pen, a large paperclip, eight different colour paper circles for the social boundary circle chart activity, coloured paper, a glue stick, a puzzle, a treat, four social story booklets and some magazines. The aSeRT manual also formed part of the training pack.

5.4.3 Measuring instrument

In order to determine if there existed appropriate published material that would be relevant for this study, a systematic literature search was conducted. The search term *measuring instr* in combination with four additional search terms, namely "knowledge", "sex*", "caregiv*", "residential care facili*" was used. The truncation symbol (*) was used as relevant in the individual databases to maximise the search results. Four databases were searched, namely PsycINFO, Educational Resources Information Clearinghouse (ERIC), Science direct Taylor and Francis and EBSCO host.

The search results were further delimited to peer review journal status and year of publication (1997 to 2013). In addition, hand search documents were included, based on reference lists retrieved documents cited, while reviews related to the sexuality knowledge and attitudes of caregivers were also examined. A total of six manuscripts were found. Four of these were excluded on the abstract level due to the following reasons: the Miller Fisk Sexual Knowledge Questionnaire, which dealt with sexuality knowledge related to reproductive physiology (Byno, Mullis & Mullis, 2009); the General Sexual Knowledge Questionnaire, which dealt with variables of sexuality such as physiology, sexual intercourse, pregnancy, contraception and sexually transmitted diseases (Talbot & Langdon, 2006), the Assessment of Sexual Knowledge Scale, which dealt with questions that elicited responses about feelings (Galea, Butler, Iacono & Leighton, 2004), and the General Sexuality Knowledge Questionnaire, which dealt with individuals with learning disabilities (Karellou, 2003). The remaining two manuscripts were read at full text level and are summarised in Table 5.1.

Table 5.1: Literature review of existing measuring instruments relevant to the current study

Measuring instrument	Areas of sexuality assessed	Scoring	Reliability and validity	Limitation/s	Implications for this study
Developmental Disabilities Sexuality Attitudes Scale (DDSAS) (Jorisson, 2008).	<p>Assesses the attitudes of paid residential caregivers about the following areas of sexuality:</p> <ul style="list-style-type: none"> different scenarios describing different situations, for example masturbating; general questions about sexuality such as sex education and masturbation of adult men and women with developmental disabilities. 	<p>Five-point Likert scale using Strongly agree; Agree; Undecided; Disagree; Strongly disagree.</p>	<ul style="list-style-type: none"> test-retest reliability Pearson correlation test = .93 retest Spearman rho = .96 	<p>The results only applied to paid residential staff members who have contact with and provide guidance to individuals with developmental disabilities. The small sample size resulted in small group sizes in the demographic analysis.</p>	<p>This study does not address the development of training materials based on the data collection, which has implications for the current study; The DDSAS provides a solid basis for developing a new measuring instrument for the specific context of the current study.</p>
Interview Questionnaire (Siebelink, de Jong, Taal & Roelvink, 2006).	<p>Assesses the knowledge attitudes, experiences and sexuality needs of people with intellectual disabilities themselves. Four topics are included:</p> <ul style="list-style-type: none"> sexual knowledge sexual attitudes sexual and relational experience sexual and relational needs <p>Two versions exist: one for males and one for females.</p>	<ul style="list-style-type: none"> Four questions on knowledge: two yes/no questions and two open-ended questions; total knowledge score counting number of correct answers. Nine questions related to sexual attitudes: response questions represented a five-point scale, visually supported by emoticons. Each question had a "don't know" option, visualised by a question mark. Seven questions: response options were 	<ul style="list-style-type: none"> reliable scale, Cronbach's $\alpha=0.69$; 	<p>Generalisability only possible with the general public based on sexual intercourse.</p>	<p>The results confirmed that relationships and sexuality are important issues in the lives of individuals with intellectual disabilities. Individuals with more sexual knowledge have more positive attitudes, and individuals with more positive attitudes have more experiences and needs.</p>

Measuring instrument	Areas of sexuality assessed	Scoring	Reliability and validity	Limitation/s	Implications for this study
		yes/no/don't know, visualised by, respectively by a thumb up and a thumb down pictogram, and question mark. • Eight questions were asked about sexual and relational needs, with some response options as above.			

A number of instruments are designed for children with intellectual disabilities but not specifically for adult women with intellectual disabilities (Morales et al., 2011). Typically, the instruments that assess the level of sexuality knowledge and attitudes do not have established psychometric properties (Ousley & Mesibov, 1991; Timmers, Du Charme & Jacob, 1981). Furthermore, the intended focus of the existing measures does not include semi-skilled caregivers within residential care facilities but rather teachers within a school programme (Wilkenfeld & Ballan, 2011). This difference in skill level posed significant research challenges, making these instruments unsuitable for the intended population of this study. Despite the psychometric properties of the two instruments, neither one is standardised for the South African context. Hence, the two instruments included in Table 5.1 were used as a basis for the development of a new instrument.

Table 5.2 gives a description of the new measuring instrument developed for the current study. It includes a discussion of the two sections of the instrument, as well as the number and types of questions included and the theoretical justification for the inclusion thereof. The newly developed measuring instrument was tested by means of a pilot study. The rationale was to determine if there were specific questions that needed to be rephrased as they were either misleading or unclear (Sarantakos, 2013).

Section A deals with biographical information. With a clearer understanding of how biographic data influences residential caregivers' attitudes about the sexuality of women with intellectual disabilities, it will be possible to create sexuality and relationship education training programmes that take into consideration the belief systems of these specific groups (Jorissen, 2008). Section B deals with the current knowledge

and attitudes of caregivers of women with intellectual disabilities towards the sexuality of these women as their beliefs and perceptions will impact on the training (Brown & Pritle, 2008; Kampalan & Li, 2009). Table 5.2 shows the measuring instrument that was developed and which was pilot tested. The adaptations that were made after the pilot study and the theoretical justification thereof is also shown in this table. The complete measuring instrument is included in Appendix F.

Table 5.2: Development of the measuring instrument

Nr	Question area	Question Formulation	Type	Theoretical justification
SECTION A: Biographical information				
This section contains 10 questions regarding the biographical background of the participants. These questions were a mix of close-ended questions, with options for example "home language": (Question 3), some open-ended e.g. "age" (Question 2).				
1	Participant number			<i>For office use only</i>
2	Age	How old are you?	Close-ended	Older caregivers are more likely to be conservative and less open about sexuality (Bouman et al., 2007; Murray & Minnes, 1994). Caregivers who are younger are more likely to be liberal in their attitudes about sexuality (Aunos & Feldman, 2002; Ryan & McConkey, 2000). Participants from different age groups will provide important data to consider for age-appropriate sexuality education (Bernert, 2011).
3	Home language	What is your home language?	Close-ended	Caregivers teach their attitudes toward sexuality via instruction and by being able to speak the same language as the women in their care, it will enhance understanding and the effectiveness of the training (Jorissen, 2008). Women with intellectual disabilities learn the caregivers' attitudes and cultural norms regarding sexuality through the socialisation process, which includes conscious and unconscious communication.
4	Religious affiliation	What is your religious affiliation?	Close-ended	Religious beliefs impact an individual's view about sexuality (Aunos & Feldman, 2002; Burling, Tarvydas & Maki, 1994; Ryan & McConkey, 2000). Religion and attitude about sexuality are closely related, as religious beliefs are what many individuals use to determine what is right and what is wrong (Lefkowitz, Gillen, Shearer & Boone, 2004). The teaching of an individual's religion provides them with the basis to make decisions about sexuality and related issues, yet often presents emotional conflict within the individual (Lefkowitz et al., 2004). Caregivers who never attended a place of worship were more in favour of people with intellectual disabilities expressing their sexuality (Ryan & McConkey, 2000).
5	Church attendance	How often do you attend church related activities?		
6	Years employed at the centre	How long have you been working at this centre?	Close-ended	Opinions and attitudes filter down to caregivers over time, in other words, the more years employed at a residential care facility the more work experience, and thus the more positive the attitudes of the caregivers towards the sexuality of the women with intellectual disabilities (Bouman et al., 2007; Karellou, 2003).
7	Total hours	In total, how many of your	Close-	The total hours per day that the caregivers spend at work in

Nr	Question area	Question Formulation	Type	Theoretical justification
	per day at work	working hours per day when on duty do you interact with the women?	ended	interaction with women with disabilities impacts on the understanding of the caregivers' influences that shape the perceptions of women with intellectual disabilities and to discover areas on sexuality education that need a common approach, with more exposure resulting in better understanding (Bazzo, Nota, Soresi, Ferrari, & Minnes, 2007; Lafferty et al., 2012). However, women with intellectual disabilities may find themselves having to adjust to different staff attitudes often as a result of a lack of a policy as a guideline (Ryan & McConkey, 2000).
8	Discussion with women about sexuality education previously	Have you ever spoken to women about sexuality before?	Close-ended	Caregivers are more likely to discuss sexuality with women who have an intellectual disability if they believe that the women have the capacity to consent to such behaviour (Christian et al., 2001; Morales et al., 2011).
9	Awareness of whether women had any previous sexuality training	Do you know if there are women who have been exposed to sexuality education training programmes before?	Close-ended	Caregivers who work with women with intellectual disabilities in residential care facilities bring their own attitudes about sexuality and about their capabilities into their environment (Tepper, 2000). Caregivers come from different backgrounds and may have different attitudes. These differences in attitude can cause confusion among women with intellectual disabilities. Therefore, a policy related to sexuality issues could serve as a guideline for sexuality and relationship education (Yool, Langdon & Garner, 2003).
10	Awareness of existing policy at the centre	Are you aware if there is an existing policy at the centre?	Close-ended	Caregivers are the primary source who enforces company policy (Christian et al., 2001). Caregivers need specific policies through which they can guide women with intellectual disabilities and teach them how to protect themselves from sexual abuse and exploitation.
11	Support of a sexuality policy	Do you support a sexuality policy?	Close-ended	If caregivers do not support the sexuality policy they will have to rely on their own decision making related to sexuality issues, which could be influenced by their personal values and own personal experiences when providing support to women with intellectual disabilities (Christian et al., 2001). In addition, caregivers are the primary source that enforces company policy.
SECTION B: CURRENT KNOWLEDGE				
This section contains 36 questions about appropriate and inappropriate touching, private and public, different types of relationships, dating and sexuality education. These aspects were directly related to the four themes covered in the aSeRT training. Participants had to answer on a five-point Likert-scale: 1=Strongly agree; 2 =Agree; 3=Undecided; 4=Disagree; 5= Strongly disagree.				
12	Appropriate/inappropriate touching	Women with intellectual disabilities know that there are different ways to touch strangers and familiar people.	Five-point Likert scale	There are times when touch and affection look out of place because the behaviour does not match what other people would expect from peers without a disability (Esmail et al., 2010).
13	Appropriate/inappropriate touching	It is important to pick up non-verbal cues from others.	Five-point Likert scale	Individuals with intellectual disabilities are less likely to pick up non-verbal cues from other people and usually require direct instruction and verbal feedback (Couwenhoven, 2007; Healy et al., 2009).
14	Appropriate/inappropriate touching	Women with intellectual disabilities have an increased need for touch	Five-point Likert	Individuals with intellectual disabilities can be indiscriminately affectionate as a result of conditioning, lack of socialisation training and stereotyping and thus need to be taught the

Nr	Question area	Question Formulation	Type	Theoretical justification
		and affection.	scale	abstract rules of different types of touch (Couwenhoven, 2007).
15	Appropriate/inappropriate touching	A handshake is an appropriate way to greet an authority figure.	Five-point Likert scale	Often the rules for touch and affection are unclear or they may change, based on culture and context (Couwenhoven, 2007; Healy et al., 2009).
16	Appropriate/inappropriate touching	Romantic touching is appropriate between caregivers and the women for whom they care.	Five-point Likert scale	Women with intellectual disabilities may need to develop and improve the understanding of appropriate and inappropriate touch; providing concrete examples may assist in achieving that (Johns, 2007).
17	Appropriate/inappropriate touching	Romantic touching is appropriate between caregivers and the women for whom they care.	Five-point Likert scale	Women with intellectual disabilities may need to develop and improve the understanding of appropriate and inappropriate touch; the provision of concrete examples may assist them in achieving that (Johns, 2007; Kampalan & Li, 2009).
18	Public and private	There are different ways to behave in public and private places.	Five-point Likert scale	When women with intellectual disabilities understand that there are public and private activities, they can learn to act more appropriately in the community (Couwenhoven, 2007; Miodrag, 2004).
19	Public and private	Because women with intellectual disabilities live in isolation their bodies do not always give them signals when they are unsafe.	Five-point Likert scale	Individuals with intellectual disabilities have limited life experiences and less information, therefore their bodies do not always give them signals when they should feel unsafe in a situation and when they need to be alert (Aunos & Feldman, 2002; Jorissen, 2008).
20	Appropriate/inappropriate touching	Women with intellectual disabilities need to be aware that their bodies belong to themselves.	Five-point Likert scale	Women with intellectual disabilities have the right to give permission to who may touch their bodies and have the sense of ownership to learn the skill to say "no" (Couwenhoven, 2007; Karellou, 2007; Siebelink et al., 2006).
21	Public and private	Teaching privacy concepts can help women with intellectual disabilities understand the rules of society.	Five-point Likert scale	By teaching women with intellectual disabilities a set of concrete and conservative rules such as appropriate greetings will help them understand the abstract rules of society in a more concrete way. Handshakes, head nods, smiles and verbal greetings are alternative ways of greeting (Jorissen, 2008).
22	Public and private	Sexuality almost always involves the idea of "public" and "private".	Five-point Likert scale	When women with intellectual disabilities know that there are designated public and private places in the residential care setting or at home, it will improve their ability to learn rules about where certain behaviours can occur (Couwenhoven, 2007; Johns, 2005).
23	Different types of relationships	Teaching women about relationships involves teaching them about social skills.	Five-point Likert scale	When teaching women with intellectual disabilities that social skills involve knowing certain rules on how to interact, they will learn appropriate behaviour in different situations (Lafferty et al., 2012; Miodrag, 2004).
24	Different types of relationships	In relationships it is important how to greet and interact appropriately in different situations.	Five-point Likert scale	Women with intellectual disabilities need to learn certain abstract rules in conversations, such as how to greet in an appropriate manner (Bleazard, 2010; Couwenhoven, 2007). Greeting is a frequently used social skill.
25	Dating	Caregivers who work in residential care facilities need to teach women how to have healthy relationships with the opposite sex.	Five-point Likert scale	Women with intellectual disabilities need to learn about boundaries in romantic relationships that will help them with decision making about what is appropriate and what not (Taggart, Truesdale-Kennedy, Ryan, & McConkey, 2012). This will also serve as a way to protect them from abuse within relationships (Bornman, 2014).
26	Different	Caregivers may have sexual	Five-	Women need to be taught who they can be romantically

Nr	Question area	Question Formulation	Type	Theoretical justification
	types of relationships	feelings for the women they take care of.	point Likert scale	involved with and with who they cannot, for example, they cannot have a romantic relationship with a family member or a paid caregiver (Johns, 2005; Wilkenfeld & Ballan, 2011).
27	Different types of relationships	Caregivers need to teach women the difference between healthy and unhealthy relationships.	Five-point Likert scale	Women with intellectual disabilities need to learn how to differentiate between different types of relationships and be taught how to identify what role different people play in different types of relationships, for example, what type of touching is allowed in what type of relationship (Healy et al., 2009; Johns, 2005).
28	Dating	Dating is a planned activity that can help women to know how to start appropriate conversations.	Five-point Likert scale	Woman need to learn how to make appropriate decisions regarding healthy and unhealthy relationships that involve both partners that show a need for dating each other (Couwenhoven, 2007; Healy et al., 2009; Miodrag 2004)).
29	Appropriate / inappropriate touching	It is okay for caregivers to touch women in a sexual way.	Five-point Likert scale	Thinking about touch within certain contexts and situations can help women with information that might help them to develop and improve their understanding of appropriate and inappropriate touch, thereby acting as a protective factor in relationships (Couwenhoven, 2007).
30	Dating	It is important that the values and the natural progression of dating are addressed with women with intellectual disabilities.	Five-point Likert scale	Teaching women with intellectual disabilities how to start appropriate conversations can help them meet new people and feel more comfortable in new social situations (Couwenhoven, 2007; Healy et al., 2009). Some of the more abstract social rules in interaction need to be made more concrete for them to be able to understand and learn these rules.
31	Different types of relationships	Romantic relationships are when two people have sexual feelings for each other.	Five-point Likert scale	Women with intellectual disabilities need to know the difference between the feelings they have when they are attracted to someone (someone with whom they can be romantically involved) as opposed to relationships with people with whom they cannot be romantically involved, such as paid caregivers and family members (Esmail et al., 2010; Johns, 2005; Swango-Wilson, 2009).
32	Dating	Teaching women to have conversations will help them feel more comfortable in their relationships.	Five-point Likert scale.	When women with intellectual disabilities know how to start a conversation, they will feel more comfortable in new social situations and be able to act in a more socially appropriate manner (Bernert, 2011).
33	Dating	Sexuality education should be taught to women with intellectual disabilities.	Five-point Likert scale	Women's understanding of their sexuality is central to their self-image and self-awareness (Lafferty, et al., 2012). This makes it imperative to also address this aspect in women with intellectual disabilities.
33	Sexuality education	Sexuality education will empower women to make responsible choices.	Five-point Likert scale	Sexuality education teaches women with intellectual disabilities what a positive relationship can be, in order for them to understand the difference between happy and unhappy relationships (Esmail et al., 2010; Johns, 2005).
34	Sexuality education	A sexuality education programme will result in more sexuality activity.	Five-point Likert scale	It is a common myth that education will result in increased sexual activity when in fact the purpose of education is to serve as a protective factor, as knowledge is seen as a form of empowerment (Brown & Pritle, 2008; Bouman et al., 2007; Wilkenfeld & Ballan, 2011).
35	Sexuality education	Women with intellectual disabilities' understanding of their sexuality is important for their self-image.	Five-point Likert scale	Women with intellectual disabilities' self-awareness impacts greatly on how they relate to themselves and others (Bonnie, 2004). Hence, self-awareness skills need to be taught in a concrete and overt manner.

Nr	Question area	Question Formulation	Type	Theoretical justification
36	Sexuality education	Women with intellectual disabilities are sterile.	Five-point Likert scale	There is a misconception that women with intellectual disabilities have a heightened sex drive and that they engage in sexual activities more frequently than their able-bodied peers (Christian, Stinson, & Dotson, 2001; Cuskelly & Bryde, 2007; Szollos & McCabe, 1995)
37	Sexuality education	Women with intellectual disabilities are oversexed.	Five-point Likert scale	Often a lack of information and reduced opportunities for socialisation contribute to social inappropriateness (Couwenhoven, 2007). This creates the false belief that women with intellectual disabilities have a heightened sex-drive (Esmail et al., 2010).
38	Sexuality education	Women with intellectual disabilities are more vulnerable to sexual abuse and exploitation than women who do not have intellectual disabilities.	Five-point Likert scale	Reasons for increased vulnerability and sexual abuse and exploitation include (i) their lack of knowledge and prior education concerning sexuality issues; (ii) their reliance on their sexuality education from non-experts; (iii) their difficulty in retaining information; (iv) their heightened trust in others due to increased supervision and (v) cultural prohibitions (Bornman, 2014; Forchuck et al., 1995; Lafferty et al., 2012).
39	Appropriate/inappropriate touching	Women with intellectual disabilities often engage in sexual behaviour.	Five-point Likert scale	There is a misconception that women with intellectual disability have a heightened sex drive and that they engage in sexual activities more frequently than their able-bodied peers (Christianson et al., 2001; Cuskelly & Bryde, 2007; Szollas & Gabe, 1995).
40	Sexuality education	Women with intellectual disabilities are asexual (they don't have sexual needs).	Five-point Likert scale	A myth exists that women with intellectual disability are asexual and that they have no sexual needs (Bornman, 2014).
41	Sexuality education	Women with intellectual disabilities experience puberty later than their able peers.	Five-point Likert scale	Unique patterns of physical development may occur depending on the individual's health. However, on average, individuals with intellectual disabilities tend to begin puberty at similar ages to their typically developing peers (Couwenhoven, 2007).
42	Different types of relationships	Sexuality involved social aspects.	Five-point Likert scale	Sexuality involves how to interact with others in a socially acceptable manner (Bernert, 2011).
43	Different types of relationships	Sexuality involved relational aspects.	Five-point Likert scale	Teaching women with intellectual disabilities how different types of relationships are similar and how they are different involves relational aspect (Swango-Wilson, 2008).
44	Appropriate/inappropriate touching	Touch is an essential part of being human.	Five-point Likert scale	There are times when touch and affection look out of place because the behaviour does not match what would be expected from peers without a disability (Couwenhoven, 2007).
45	Dating	Caregivers need to teach women with intellectual disabilities to be more assertive.	Five-point Likert scale	If caregivers teach women with intellectual disabilities how to be more assertive, they will be less likely to allow others to take advantage of them, resulting in greater freedom and independence (Wilkenfeld & Ballan, 2011).
46	Sexuality education	Individuals with intellectual disabilities touch others inappropriately because of social isolation.	Five-point Likert scale	Women with intellectual disabilities have the right and need to relate to their own sexuality, the right to privacy and dignity, and the need to express their feelings related to sexuality. Their right to be free from sexual exploitation and harm is most important (Bleazard, 2010; Wilkenfeld & Ballan, 2011).
47	Sexuality	Women with intellectual	Five-	Sexuality education is a protective factor for women with

Nr	Question area	Question Formulation	Type	Theoretical justification
	education	disabilities have a right to sexuality education.	point Likert scale	intellectual disabilities (Bornman, 2014; Wilkenfeld & Ballan, 2011). In addition, the availability of resources related to sexuality education, adds to psycho-educating women with intellectual disabilities to protect themselves from sexual abuse and exploitation.

Table 5.2 showed the development of the measuring instrument which was pilot tested and adapted. It described the question area, the question type and the specific question formulation and included a theoretical justification for the inclusion of the specific questions.

5.4.4 Training Evaluation Form

At the end of the two-day, custom-designed training using the aSeRT, participants were asked to complete a training evaluation questionnaire. The development of this questionnaire is shown in Table 5.3. The table shows the question area, the question formulation as well as the justification for inclusion. The rationale for this training evaluation instrument was to determine the applicability and usefulness of the training manual with the training pack, the ease of its use and the instructions given, and to determine whether the participants agreed that the training programme could be generalised to other residential care facilities. The complete evaluation form is included in Appendix G.

Table 5.3: Training evaluation form

Question number	Question area	Question formulation	Justification for inclusion
This questionnaire consisted of 24 questions in eight sections, and comprised seven three-point Likert scale questions (Agree=1; Unsure= 2; Disagree= 3); one question on a five-point Likert scale (1= Very poor to 5 =Very good); one open-ended question; four questions about the training objectives, six questions about the training procedure objectives on a three-point Likert scale; one yes/no question and five questions about the pre-and post-questionnaire objectives on a three-point Likert scale.			
1	Presentation	The trainer was well prepared for the training.	Preparation enhances the general quality of the training, and put participants at ease by focusing on an interactive form of learning where the trainer and the caregivers are equal partners in the learning process (Du Toit, et al., 2003).
2	Planning	The training sessions were logically planned and presented.	One of the most important principles of good teaching is the need for planning (Spencer, 2003). With planning it is important to evaluate if the sequence of the themes presented in the training follows logically after one another. It is important to observe what is happening in each presentation of the themes and if the themes are relevant and appropriate in terms of planning (McKenzie et al., 2013).
3	Length	The length of the training was sufficient.	To evaluate if the length of the two-day, custom-designed sexuality and relationship education programme was sufficient.
4	Usefulness	The programme will	To evaluate if the training was useful/valuable to the caregivers to

Question number	Question area	Question formulation	Justification for inclusion
		definitely be useful for our institution as well as others.	increase their knowledge and change their attitudes on sexuality related issues of women with intellectual disabilities (Bennett, 2007).
5	Format	There were enough opportunities for participation during training (activities).	To evaluate if there were sufficient opportunities for hands-on participation in the training programme. It is important to observe the caregivers' interaction and participation during icebreakers, activities and cool-down activities and if they need recommendation for change to be more suitable for the context within which the caregivers look after women with intellectual disabilities (Bennett, 2007).
6	Usefulness	The training will help me and other caregivers deal better with women who have intellectual disabilities and sexuality issues.	To evaluate if the training was useful/valuable to the caregivers to increase their knowledge and change their attitudes on sexuality related issues of women with intellectual disabilities. Although the programme was custom-designed it contained generic features that would transfer to other contexts.
7	Satisfaction	I would recommend this training to other caregivers who work with women with intellectual disabilities.	There is an imperative need to attend to participant satisfaction after training when evaluating the effectiveness of training (Torrow & Witey, 2006). Research has shown that one of the most important factors in satisfaction is the opportunity to learn new skills (Schmidt, 2007).
8	Satisfaction	What was the overall value of the training session?	To determine the overall value/contribution of the training session as perceived by participants themselves, as their perception of the value will predict how they will implement it (McKenzie et al., 2013).
9	Further training needs	Comments and suggestions.	Comments and suggestions for further training from participants for the training programme, to capture additional information (McKenzie, et al., 2013).
10	Training aspects	Which three aspects of the training did you enjoy most?	An open-ended question was used to ensure that relevant information would not be neglected or overlooked. This was also effective for obtaining participants' own views.
11	Ease of use	The training material provided was easy to use and the instructions simple to follow.	To test the ease of use of the training programme. Ease of use was an important consideration in the development of the study, given the skill levels of the participants (Lanigan, 2010). The training used a writing style that was easy to read and free of jargon, except in cases where the terms were specifically defined beforehand.
12	Activities	The activities of each module was appropriate and easy to execute.	To evaluate the appropriateness of the activities included in the training programme (Lafferty et al., 2013). Appropriate activities enhance the knowledge and skills learned in training, and create exciting, liberating, motivational opportunities while enabling learning and development (Nischitha & Rao, 2014).
13	Social stories	The social stories were easy to read and the pictures disability friendly.	To evaluate the ease and usability of the social stories with pictures (Gray, 2003). An easy writing style using active voice was used with images to enhance the writing (Lanigan, 2010). Attempts were also made to ensure that the stories were visually appealing by including only one image per page.
14	Appropriateness	In general, the training is appropriate for the sexuality and relationship education for caregivers.	Caregivers will be observed during role-play activities, actively using the sexuality and relationship education training programme and asked to rate the ease of using it.
15	Material	The training material provided was easy to use and the instructions simple to	Training material was compiled in a visually appealing manner with sufficient wide space as to not confuse participants (Lanigan, 2010). Furthermore, easy-to-understand language was used.

Question number	Question area	Question formulation	Justification for inclusion
		follow.	
16	Instructions	The instructions for the activities were easy to follow in the training programme.	All instructions should be understandable and easy to follow in order to prevent activities from being executed in an inappropriate or unplanned manner, thereby wasting valuable training time (Case, 2010). Some strategies that were used included writing activities down, checking if participants understood by eliciting instructions ("What do you think I want you to do?") using pictures and emphasising key words (Case, 2010).
17	Teaching aids	The teaching aids used by the trainer were relevant and enhanced my understanding of sexuality education and relationships.	Including teaching aids such as the sexuality and relationship education training manual and other equipment and material will determine the suitability of the physical presentation (Johns, 2005). These teaching aids enhance the ease of learning and maximise retention. Teaching aids attempted to use activities that the participants were familiar with, such as puzzles, using ample demonstrations, role-playing, how the aids should be used and using the same language (Case, 2010).
18	Material	The training material used was adequate and useful.	To evaluate the appropriateness and usability of the training material. Low technology material that was easily available was used, for example, magnets, string and paper, as this material was relevant for the specific context (Lanigan, 2010).
19	Instructions	The instructions given by the trainer were clear.	To test the clarity and preciseness of instructions given by the trainer, in order to increase the accuracy with which participants could follow the instructions (Case, 2010).
20	Relevance	The essence of sexuality and relationship education is captured in the training programme.	The programme was custom-designed following the use of three different focus groups in Phase 1, in an attempt to heighten relevance. If participants can identify with the content and find the training relevant, it increases satisfaction and enhances learning (Torow & Wiley, 2006).
21	Timing	The length of time per day was sufficient.	To evaluate the length of the training that will take place over a period of two consecutive days from 08:00 – 16:30.
22	Terminology	I was familiar with the terminology used in the questions.	To evaluate familiarity with and understanding of the terminology used in the questionnaire. Using clear language results in reliable responses (Lanigan, 2010).
23	Instructions	The instructions in the training manual were clear and easy to follow.	To test the clarity and preciseness of instructions used in the training manual. The same considerations regarding instructions related to the training material were used (Case, 2010).
24	Order of themes	The ordering of the different themes was sensible.	To determine if participants felt that the various themes followed each other logically and built on previous knowledge.

The rationale for this training evaluation was to determine how effective the training was in terms of acquiring new knowledge and fostering positive attitudes, and to determine participants' subjective evaluation of the training related to a broad range of aspects.

5.5 PILOT STUDY 1

5.5.1 Aims

The overarching aim of Pilot Study 1 was to evaluate and test the applicability of the measuring instrument and the concepts used to test knowledge and attitudes about sexuality related issues of caregivers working with women with intellectual disabilities in residential care facilities.

5.5.2 Description of Setting

A residential care facility in the Gauteng area was selected for the pilot study, due to many similarities with the facility selected for the main study, namely the same geographical area, functioning of the facility, the service delivery model as well as the caregivers' profile. Permission was obtained from the director of this facility to conduct the research at the site (Appendix H). In order to realise the objective of the pilot study it was essential that the pilot study was highly comparable to the main study.

5.5.3 Participants

- i) The participants in the pilot study were subjected to the same selection criteria as the participants in the main study (see Section 5.8.1).
- ii) Ten caregivers who provide direct care to the women with intellectual disabilities at the particular residential care facility and who could potentially participate were selected. Eight of the caregivers were female and two were male.
- iii) Written informed consent was obtained from all participants.
- iv) All caregivers from the residential care facility completed the biographical background information section of the measuring instrument (Section 1) to ensure that they adhered to the selection criteria of the study.
- v) To include as many participants as possible, the criterion focused on the number of years of experience at the facility was relaxed, and hence some participants only had one month's experience.

In Table 5.4 the biographical information of the ten participants who participated in Pilot study 1 is presented.

Table 5.4: Biographical information of participants in Pilot 1 (N = 10)

Participants	P1.1	P1.2	P1.3	P1.4	P1.5	P1.6	P1.7	P1.8	P1.9	P1.10
Gender	Female	Female	Female	Female	Female	Female	Male	Male	Female	Female
Age	41 years	26 years	28 years	34 years	29 years	30 years	24 years	27 years	24 years	30 years
Home language	Sesotho	Sesotho isiZulu	Sesotho	Sesotho	Other	Sesotho	Sesotho isiZulu	Sesotho isiZulu	Sesotho	isiZulu
Religious affiliation	Christian	Christian	None	Christian	Christian	Christian	Christian	Christian	Christian	Christian
Church attendance	Once a month	Once a week	Once a month	On special occasions	On special occasions	Once a week	Once a month	More than once a week	Once a month	Once a week
Years working at the facility	1 year	1 month	3 years	8 years	1 month	4 years	1 year	4 years	1 year	2 months
Hours working per day	8 hours	2 hours	2 hours	6 hours	8 hours	8 hours	2 hours	8 hours	8 hours	8 hours
Spoken about sexuality to women	Yes	No	No	Yes	Yes	No	No	No	No	Yes
Awareness of women exposed to sexuality education previously	Unsure	No	Unsure	Unsure	Unsure	No	Yes	Yes	Unsure	Unsure
Awareness of existing sexuality policy at the facility	Unsure	No	No	Yes	Unsure	No	No	No	Unsure	No
Support of sexuality policy	Yes	Yes	Yes	Yes	Unsure	Yes	Yes	Yes	Unsure	No

Table 5.4 shows that seven participants worked at the residential care facility for at least six hours or more per day and that seven had worked for one year or more. From this table it is also evident that only four of the participants had spoken to the women with intellectual disabilities about sexuality education before training. Six participants were unsure if the women with intellectual disabilities had been exposed to sexuality education previously, while two said no. Only two participants were aware of the women having been exposed to sexuality previously. Only one participant was aware that the residential care facility had an existing sexuality policy, while three were unsure, and six thought that it did not have a policy. Seven stated that they would support a sexuality policy.

5.5.4 Procedures

The first training date was scheduled for a Monday and Tuesday but postponed to the Tuesday and Wednesday, as Monday is regarded as “clinic day” and on these days caregivers are required to accompany residents of the facility to a health care clinic. The pilot study took place over two consecutive days. Caregivers were excited and enthusiastic to receive the training. The same steps outlined for the main study were followed and the measuring instrument was completed before and after training.

5.5.5 Objectives, Results, Recommendations Following the Pilot

The objectives, results and recommendations of Pilot Study 1 are given in Table 5.5.

Table 5.5: Objectives, materials and equipment, procedures, results and recommendations following Pilot Study 1

Rationale	Materials & Equipment	Procedures	Results	Recommendations
To evaluate the sexuality and relationship education training programme with regards to the following objectives: Privacy and appropriate conversations				
Theme 1: Appropriate and inappropriate touching				
To evaluate the effectiveness of <i>icebreaker 1</i> for setting the group at ease, practicing turn-taking skills and talking and listening to each other.	Greetings permission game	Participants had to turn to the person sitting next to them, working in pairs. Participants had to tell their partners something about themselves, such as their favourite food or favourite hobby, and then share it with the group.	A relaxed atmosphere was created among the group, with lots of laughter, and acknowledgement of each other's contribution, for example, "I also love to eat". Focused listening was observed, as participants were interested in each other's responses.	This activity was effective in obtaining the required effect and meeting the objectives, as turn-taking with appropriate listening was observed. This activity should remain in its current format for the main study.
The determine the appropriateness of <i>Social Story 1</i> aimed at teaching social boundaries as well as reinforcing healthy boundaries within relationships, which involves knowing the rules of different interactions in different situations.	Social Story 1: All about hugs. Proxima projector Laptop	Social Story 1 was read to the participants. While reading the story, the trainer simultaneously pointed to the pictures on the PowerPoint slides. In addition, each participant also received her own printed version of Social Story 1.	Seven of the participants preferred to follow the printed version of Social Story I. They did, however, not page through the whole social story on their own, but stayed with the trainer turning the pages at the appropriate time. Three participants preferred following the PowerPoint presentation of the story.	Although the majority of participants followed in the printed version, some enjoyed the electronic version. Therefore, it is suggested that both presentation methods be retained for the main study, in order to include different learning styles.
To gauge the appropriateness and ease of the <i>activity</i> included in Theme 1.	Activity: Asking permission Piece of string (1.5m)	Participants were paired in groups of two by the trainer. A piece of string was placed into a circle shape around one of the participants in the pair, while the other remained outside. The trainer then emphasised personal boundaries demonstrating that the person on the outside of the circle had to ask permission from the inside person before joining her in the circle.	Participants on the outside of the circle realised that they could not simply walk into the circle without asking permission. On the other hand, the participants on the inside of the circle realised that they had the power to decide if they wanted to open the circle or not. Seven participants stated that they never before thought of asking permission to be close to the women in their care, and they also did not realise that these women could refuse having them in their personal space. They also expressed concern for how to deal with situations when one of the partners over stepped the boundaries.	This activity concretised the abstract concept of personal space and boundaries. Participants also stated that they found this activity easy to understand, and they thought that they would be able to use this exact same activity to explain to the women in their care how important boundaries were. They felt that they had learned a new skill which was easily transferable, and therefore it is recommended that this activity remains exactly the same in the main study.

Rationale	Materials & Equipment	Procedures	Results	Recommendations
To appraise the effectiveness of the <i>cool-down activity 1</i> in ending the session in a relaxing and fun way.	Cool-down activity one: Big fish small fish	The trainer divided the ten participants into two groups of five each. The leader of each group was asked to hold her hands together. When instructed by the leader, "big fish", they indicated "big" by separating their hands and bringing their hands together to indicate "small fish." The hesitant participants were eliminated. The game continued until the second last participant was eliminated and the winner received a prize.	This cool-down activity worked effectively in the group, and facilitated excellent listening skills, as the participants could not predict if the instruction would be "big fish" or "small fish". When each participant was excluded it resulted in lots of laughter, and the eliminated participants enjoyed observing who hesitated and who would be "out" in the next round. They participated actively, as they all wanted the winner's prize. They also enjoyed the fact that they did not remain in the same groups for the whole training. Being part of different groups led to greater group cohesion. When the activity ended, they were reluctant to leave the session, as they exclaimed that they were having fun.	Following the seriousness of the previous activity, this playful activity resulted in ending the theme on a high note. Participants were relaxed and it was noticeable that they were having fun. They were also enthusiastic to continue with the training, asking if it would continue being so much fun. It is therefore recommended that this activity be repeated in exactly the same manner and in the same sequence in the main study.
Theme 2: Public and private places				
To evaluate the effectiveness of <i>icebreaker 2</i> for setting the group at ease, practicing turn-taking, group collaboration as a problem-solving skill by participants, each contributing their own skills to the exercise.	Reading a map: A3 size paper Koki pens Prestik	The trainer divided the ten participants into two groups of five each. The leader of each group was asked to direct their group in drawing a road map that represents going on a narrative journey representing sexuality education. Each group was represented by a designated driver (the leader of each group), who had to navigate them to their destination.	The trainer had to explain comprehensively to the leaders as well as to the groups what was meant by the drawing of a road map. Participants explained that they make use of public transport instead of private transport and therefore never use or need a map. This resulted in misconception. The trainer attempted to explain the icebreaker activity in different terms by using terms such as "road signs", "potholes", "stop signs" and "traffic lights". The participants still had difficulty executing the task.	This journey activity as a narrative for sexuality education to teach participants how to navigate women with intellectual disabilities was unsuccessful and it is recommended that the activity be replaced with "Activity Cards". This implies that the new icebreaker will need to also be piloted first.
To determine the appropriateness of <i>Social Story 2</i> aimed at the understanding that there are public and private places	Social Story 2: Public and private places Proxima projector Laptop	Social Story 2 was read to the participants. While reading the story, the trainer simultaneously pointed to the pictures on the PowerPoint slides. In addition,	After reading Social Story 2 the trainer asked for comments related to the appropriateness of the context. Participants agreed that it was unsuitable for the following reasons: (i) the women	In an attempt to teach women with intellectual disabilities how to act more appropriately within social contexts within their immediate environment, it is recommended that

Rationale	Materials & Equipment	Procedures	Results	Recommendations
and public and private activities.		each caregiver also received their own printed version of Social Story 2.	with intellectual disability share bedrooms with approximately five to six other women, and for this reason their bedrooms do not qualify as a "private place"; (ii) the women would not understand the word "tinkle" (urinate); (iii) the women with intellectual disability live in isolation and therefore do not have the opportunity to go to movies, a coffee shop or the mall, where they are exposed to public places.	Social Story 2 is re-written, focusing on the importance of social appropriateness related to privacy and confidentiality related to "happy" and "unhappy" secrets. This social story will need to be piloted first.
To gauge the appropriateness of the <i>activity</i> included in Theme 2.	Collage: Individual work Old magazines A3 size paper Glue Scissors A5 cardboard cut in half Labels with public and private statements	The trainer provided each participant with a piece of A3 size paper as well as magazines. The A3 size paper was divided in half, the left side of the paper labelled "private places" and the right side labelled "public places". The participants used the magazines to look for pictures to cut out and create collages that show the differences between public and private places.	This activity worked well. However, when participants had to apply this specific activity to training women with intellectual disability, they stated that it would not be suitable, as the women with intellectual disability share their bedrooms with at least five other women so this would not qualify as a "private place" and, as a result of their isolated lifestyles, they do not have the opportunity to go to shopping malls or the movies. Therefore, their privacy is violated on several levels.	It is recommended that this activity be replaced with a "Dare to share activity" which will be piloted before the main study with the following questions included: "Who is your favourite singer?" "Do you sometimes eat your dessert before your food?" "What is your favourite programme on television?" "Who is your role model?" "Do you snore?" "Do you sing in the bath/shower?" "Do you talk to yourself?"
To appraise the effectiveness of <i>cool-down activity 2</i> in ending the session in a relaxing and fun way.	"Public" and "private"	After the trainer explained the differences between public and private places, the participants had to label various rooms within the residential care facility with "public" or "private" labels or symbols.	This activity is not appropriate within a residential care facility as the residents share bedrooms with several others.	It is recommended that this activity be replaced with an exercise about "happy" and "unhappy secrets". A5 size coloured paper/cardboard will be used. Each participant will receive two pieces of A5 size paper/cardboard, one labelled "happy" secrets and the other cardboard labelled "unhappy" secrets. The participants need to write on each of their cards what they perceive as a "happy" secret and an

Rationale	Materials & Equipment	Procedures	Results	Recommendations
				"unhappy" secret and then share it with the group in a discussion format.
Theme 3: Different types of relationships				
To evaluate the effectiveness of <i>icebreaker 3</i> for setting the group at ease, practising, turn-taking skills and talking and listening to each other.	Magnet Large paper clip Pencil made from plastic A treat	The trainer demonstrated how a magnet and a large paper clip stick together. This activity was used as a narrative to demonstrate that when two people are attracted to each other, they want to feel close to each other, feel excited and happy when they are together.	This activity aimed at introducing the idea of mutual attraction in a loving and sexual relationship. The participants could discover what the magnets were and were not attracted to, which enhanced the understanding of attraction and trust between two people. The idea that attraction included both individuals was highlighted.	This activity was effective in obtaining the required effect and meeting the objectives, as turn-taking with appropriate listening was observed. This activity should remain in its current format for the main study.
The determine the appropriateness of <i>Social Story 3</i> aimed at explaining how relationships are similar or different	Social Story 3: Different types of relationships Proxima projector Laptop	Social Story 3 was read to the participants. While reading the story, the trainer simultaneously pointed to the pictures on the PowerPoint slides. In addition, each participant also received their own printed version of Social Story 3.	Seven of the participants preferred to follow the printed version of Social Story 3. They did, however, not page through the whole social story on their own, but stayed with the trainer turning the pages at the appropriate time. Three participants preferred following the PowerPoint presentation of the story.	Although the majority of participants followed in the printed version, some enjoyed the electronic version. Therefore, it is suggested that both presentation methods be retained for the main study in order to include different learning styles.
To gauge the appropriateness of the <i>activity</i> included in Theme 3.	Social Boundary Circle chart Proxima projector Laptop Glue Magazines Scissors Pictures	Participants were asked to identify people in their lives who were most important to them. Magazine pictures were used to represent these people. The participants were then asked to stick the picture on the boundary circle chart. Each circle represented a relationship category of the person or people they love and trust.	The participants were excited to participate in this activity and in addition, it re-defined the importance of significant others within the lives of the caregivers. At the end of the training, four of the participants commented that the Social Boundary Circle Chart was one of their favourite activities.	This activity was effective in obtaining the required effect and meeting the objectives, as turn-taking with appropriate listening was observed. This activity should remain in its current format for the main study.
To appraise the effectiveness of <i>cool-down activity 3</i> in ending the session in a relaxing and fun way.	Phone a friend/colleague Cell phone	The trainer placed a phone in the circle of participants and pretended it was ringing. A volunteer was asked to answer the "phone call" and pretend to have a conversation. The other caregivers had to guess what her relationship was with the	The participants enjoyed this activity and there was quite some laughter and enjoyment happening during the activity. They were able to always correctly evaluate where on the Social Boundary Chart, the person who was phoning fitted. They stated that they had never before	This playful activity resulted in ending the theme on a high note. Participants were relaxed and it was noticeable that they were having fun. They were also enthusiastic to continue with the training, asking if it would continue being so much fun. It

Rationale	Materials & Equipment	Procedures	Results	Recommendations
		caller by listening to her conversation skills and observing her body language to identify the person with whom she was talking.	thought about phone calls in this manner.	is therefore recommended that this activity be repeated in exactly the same manner and in the same sequence in the main study.
Theme 4: Romantic relationships				
To evaluate the effectiveness of <i>icebreaker 4</i> for setting the group at ease, practising turn-taking skills and talking and listening to each other.	Labelling favourite animals Labels Koki pens	Each participant received an empty label and was requested to write the name of their favourite animal on the label without showing it to the other participants. Each participant had the opportunity to choose her own partner for this activity. The rest of the group would then observe. The participant placed her label on her partner's forehead without knowing what animal's name was written on the label. She then needed to ask relevant questions and act out the animal's behaviour for the other person to be able to guess the correct animal.	The participants seemed to really enjoy this particular activity as there was a lot of laughter and excitement among the group during the turn-taking between pairs. Depending on questions asked and the animal chosen, two participants struggled to identify their partner's animals, namely a dove and a giraffe. This concludes that this activity focuses on the listening skills of the receiver and the communication skills of the sender. One of the participants specifically highlighted in the training evaluation form that this activity was one of the icebreakers that she enjoyed the most.	This activity is recommended for the main study as it enhances communication skills by the sender and listening skills by the receiver. In addition, it adds to interaction on a social level that is appropriate. Working in pairs also ensured that all the participants remained actively involved.
To determine the appropriateness of <i>Social Story 4</i> aimed at teaching women about boundaries in romantic relationships.	Social Story 4: Dating Proxima projector Laptop	Social Story 4 was read to the participants. While reading the story, the trainer simultaneously pointed to the pictures on the PowerPoint slides. In addition, each caregiver also received their own printed version of Social Story 4.	As with Social Story 1, seven of the participants preferred to follow the printed version of Social Story 4, while three preferred following the PowerPoint. Participants commented that as a result of the women with intellectual disabilities' isolation they have limited access to a pool of dating partners and therefore this story was inappropriate. Participants did not have the opportunity to go "on a date", making dating an abstract and foreign concept.	It is recommended that sections of Social Story 4 be re-written, focussing on more relevant aspects, such as their peers within the residential care facility. Furthermore, skills to distinguish between "inappropriate" and "appropriate" dating partners (conversation related) as well as "happy" and "unhappy" secrets should be included. The title of Social Story 4 should be changed to "Romantic Relationships" rather than "Dating".
To gauge the appropriateness of the <i>activity</i> included in Theme	Mr and Mrs Right Sweets Written journey	The trainer had the group stand in a circle giving each participant a sweet to keep in their right hand.	Participants seemed to struggle with this activity. The trainer joined the participants in the activity to try and make it easier for	It is recommended that this activity be replaced with a group activity by building a puzzle of a group photo

Rationale	Materials & Equipment	Procedures	Results	Recommendations
4.		Then the trainer told the story of Mr and Mrs Right going on a trip to the Drakensberg. Every time the trainer used Mr or Mrs Right's name, every member in the group had to pass the sweets to the person standing on their right. When indicating that Mr Right turned to the left, every participant in the group had to pass the sweets to the person on their left, until Mr and Mrs Right reached their destination.	them to understand the instructions. Although one of the participants said that this was one of the activities that she enjoyed the most, the majority struggled with listening and doing the activity at the same time. After the third attempt to repeat the activity, the trainer realised that the activity was not going to be successful.	taken by the trainer to enhance the understanding and collaboration of teamwork within the residential care facility.
To appraise the effectiveness of <i>cool-down activity 4</i> in ending the session in a relaxing and fun way.	Pen Paper	The trainer gave each participant an opportunity to share with the group what they have learned about themselves during the training.	Various comments were made, namely "not taking things for granted"; "the trainer made it fun to learn"; "the importance of rules"; "personal space"; "the different types of relationships, for example, romantic and friendship"; "underestimated how much I do not know about the topic"; "the training was fun and the social stories were easy to read and understand"; "it reminded me again of the importance of the passion I have for what I am doing"; "to take the issue more seriously"; "the social stories and how to use them". The cool-down activity was effective to reflect on what they did in the training as well as reflect on what they learned in the social stories and activities.	The cool-down activity's aim was to reflect on the questions: "what have I learned about myself during the training? If I could give a star to anybody in the group I would give it because ...why would it be and to whom? This activity was effective for the group to reflect and to remember what they did during the training and what they learned and enjoyed most. This activity should be maintained in exactly the same way in the main study.
TO EVALUATE THE MEASURING INSTRUMENT WITH REGARDS TO THE FOLLOWING OBJECTIVES:				
To determine the appropriateness of the terminology used in the measuring instrument and the suitability of the different questions.	Measuring instrument: pre and post-test	The participants were asked to complete the measuring instrument on Day 1 before the training and the post-test on Day 2 after the training without discussing the questions with each other. The trainer was	The terminology used in some of the questions made the question unclear, in other words, the participants were unsure if the questions were referring to them, or at the women in their care. As a result, three questions (Questions number 12,	Please refer to Table 5.10 for a complete discussion of how the measuring instrument was changed. This table contains the detail regarding each specific question. All questions related to the new

Rationale	Materials & Equipment	Procedures	Results	Recommendations
		available throughout.	14 and 44) were refined by adding a word or two to make this clearer. In addition, six questions were rephrased (keeping the intent of the question the same, but changing the outline of the question (Questions, 13, 15, 17, 18, 28 and 43). As one theme was not applicable to the women with intellectual disabilities and the content of one theme was modified, 12 questions had to be re-written (Questions 19, 20, 21, 22, 23, 24, 25, 26, 27, 29, 30, 31, 32 and 45).	Theme 2, "Privacy and Appropriate Conversations" were re-written to reflect this new theme. For example, "Secrets can be divided into happy secrets and unhappy to show the intent of the person who asks for the secret". All questions related to dating were rephrased using the terminology "romantic relationships".
To determine if the instructions were clear and easy to follow.	Measuring instrument: pre and post-test	The trainer was available at all times to address any potential uncertainties.	All the participants agreed that the instructions were clear and easy to follow. Some questionnaires were incomplete, but when discussing this with the participants, they stated that this was not due to the instructions but because they accidentally omitted the question, or because they were unsure about their answer.	The instructions will remain the same for the main study. It is recommended that the trainer check the questionnaire in the main study to make sure that all the questions have been answered after completion by the participants, so that "missing data" is avoided.
To determine the amount of time required by participants to complete the questionnaire in order to plan time allocation for the main study.	Measuring instrument: pre and post-test Timer	The trainer used a timer to determine the amount of time needed to complete the questionnaires (pre and post training).	The pre-test needed more time to complete as it also contained the 11 biographical questions. The time ranged from 20 min. to 45 min, with an average of 30 min. The post-test was completed in less time. Apart from the fact that biographical questions were excluded, the content was more familiar to participants. The time ranged from 18 min. to 40 min, with an average of 25 min.	It is recommended that between 30 and 40 minutes be allocated for participants to complete the pre-training questionnaire in order to allow them with sufficient time to consider their choices. For the post-training questionnaire, 30 minutes will be sufficient time allocation to allow participants the opportunity to complete the questionnaire.
To determine if the ordering of the questions was sensible.	Measuring instrument: pre and post-test	The order of the questions in the measuring instrument followed the same sequence as the order of the training, starting with Theme 1 and ending with Theme 4.	Due to the fact that some questions had to be adapted to accommodate the new theme (romantic relationships versus dating) the order to 12 questions was changed. Question 33 changed to 36; 34 to 37; 35 to 38; 36 to 39; 37 to 40; 38 to	The changes made to the measuring instrument are described in detail in Table 5.10. The re-ordering of the questions reflected the flow of the themes, and the questions related to broader aspects of the training, were

Rationale	Materials & Equipment	Procedures	Results	Recommendations
			41; 39 to 42; 40 to 43; 41 to 44; 42 to 45; 46 to 48; and 47 to 50.	asked last (after Theme 4). This ensured a conceptual intactness of information for the participants.
To determine the appropriateness of the five-point Likert scale	Measuring instrument	Participants had a choice between five answers: 1=Strongly agree, 2=Agree; 3 = Undecided; 4= Disagree; 5= Strongly disagree.	The choice of using a Likert scale did not work well as some of the participants did not answer many of the questions or chose the option "unsure".	It is recommended that the type of response is changed to a binary type scale: true/false, given the fact that the questions are knowledge-based.
TRAINING EVALUATION				
Presentation of training	Training evaluation form	Participants completed the training evaluation form without discussing the questions with each other. The trainer was available throughout.	All participants agreed that the training sessions were logically planned and presented. However, some of the sessions seemed to be exhausting for the participants.	It is recommended that during the training of the main study that the trainer uses discretion to allow more frequent breaks for the participants when needed.
Overall rating of training session	Training evaluation form	Participants completed the training evaluation form independently.	All participants rated the overall training session on the Likert Scale with a score of 5 = very good.	Training is retained in the same way, implementing recommendations as discussed.
Length of training session	Training evaluation form	Participants independently completed the training evaluation form.	All participants agreed that the length of the training sessions was sufficient. However, during Day 2 it was observed that some of the participants were tired earlier during the training.	It is recommended that more frequent breaks are allocated during the training on day two, as the trainer observed fatigue.
Usefulness of the programme for the institution and others	Training evaluation form	Participants completed the training evaluation form without discussing the questions with each other.	Nine participants agreed that the programme would definitely be useful for the institution, but one participant, who works at a residential care facility for the elderly, disagreed. The trainer was unaware of this fact when training commenced.	It is recommended that the trainer ensures that all participants meet the selection criteria beforehand, as it is a custom-designed programme.
Opportunities for participation during training	Training evaluation form	Participants completed the training evaluation form independently.	All participants agreed that there were enough opportunities during the activities for them to participate during training.	Activities for the main study will remain the same to create opportunities for participation in a group and as individuals.
Training will assist caregivers in dealing with sexuality issues of women with intellectual disabilities	Training evaluation form	Participants completed the training evaluation form without discussing the questions with each other.	All participants agreed that the training will assist them in dealing with sexuality related issues of women with intellectual disabilities, and that it is an important	This training is recommended for the main study with some content adaptations as recommended.

Rationale	Materials & Equipment	Procedures	Results	Recommendations
Recommendation of training to other caregivers	Training evaluation form	Participants completed the training evaluation form independently.	<p>concept to discuss.</p> <p>All participants stated that they would recommend this training to other caregivers who work with women with intellectual disabilities.</p>	The new suggested "Theme 2" can be provided to the same participants as a refresher course.

From the above table it is clear that changes were required after the pilot study. These changes were mostly with regards to Theme 2 of the aSeRT and to Section B of the measuring instrument. All the questions were changed to include *“women with intellectual disability”* to ensure that the attitudes of caregivers enhance perspective on the sexuality and relationship of the women with intellectual disabilities for whom they take care. In cases where it is indicated that the questions remained the same, small changes, for example, adding *“women with intellectual disabilities”* were recommended, but the general gist of the question remained unchanged. Questions related to Theme 2 were changed to reflect the new theme focus. The rationale for refining and/or rephrasing questions was to avoid potentially unclear or misleading formulations (Sarantakos, 2013). The original measuring instrument was tested by means of a pilot study. The rationale was to demonstrate if the responses of the pre-test and post-test indicated that specific questions needed to be rephrased, being either misleading or unclear (Sarantakos, 2013).

5.5.6 Summary

Following the pilot, recommendations to the measuring instrument were suggested and subsequently made. Theme 2 was also re-written to focus on *“privacy”* and *“happy”* and *“unhappy”* secrets as opposed to the original *“public and private places”* as well and minor changes to Theme 4, namely replacing *“dating”* with *“romantic relationships”*. In order to test the appropriateness of the new Theme 2 and the new measuring instrument, a further pilot study (of limited scope) was suggested. As these two aims were distinctly different, the testing of the new Theme 2 resulted in Pilot Study 2, while the measuring instrument resulted in Pilot Study 3. See Appendix I for a photo collage of Pilot Study 1.

5.6 PILOT STUDY 2

A second pilot study was not originally envisaged, but following the outcomes of Pilot Study 1 it became evident that the newly developed Theme 2 would also need to be piloted in a similar way to Pilot Study 1.

5.6.1 Aims

The overarching aim of Pilot Study 2 was to evaluate and test the applicability of the new Theme 2.

5.6.2 Description of setting

The same residential care facility within the Gauteng area that was used to conduct Pilot Study 1 was used for Pilot Study 2.

5.6.3 Participants

The participants in Pilot Study 2 were subjected to the same selection criteria as the participants in Pilot Study 1 (see Section 5.5.3). Only five caregivers met the selection criteria and were available to participate, as the other caregivers could not be relieved from their job responsibilities. Three of the five participants also participated in Pilot Study 1, while two participants were new. Table 5.6 shows the biographical data of the participants in Pilot Study 2.

Table: 5.6: Biographical information of participants Pilot 2 (N=5)

Participant	P2.1 former (P1.2)	P2.2 former (P1.8)	P2.3 former (P1.9)	P2.4 (new)	P2.5 (new)
Gender	Female	Female	Female	Female	Female
Age	26 years	24 years	27 years	33 years	22 years
Home language	Sesotho isiZulu	Sesotho	Sesotho isiZulu	isiXhosa	isiZulu
Religious affiliation	Christian	Christian	Christian	Christian	Christian
Church attendance	Once a week	Once a month	More than once a week	Once a month	Once a month
Years working at the facility	1 year	1 year	4 years	3 years	2 years
Hours working per day	2 hours	8 hours	8 hours	8 hours	8 hours
Spoken about sexuality to women	No	No	No	Yes	No
Awareness of women exposed to sexuality education previously	No	Unsure	Yes	Yes	No
Awareness of existing sexuality policy at the facility	No	Unsure	Unsure	Yes	Unsure
Support of a sexuality policy	Yes	Unsure	Yes	Yes	Yes

Table 5.6 shows that four participants worked at the residential care facility in a full-time capacity (eight hours per day), except for one who worked only part-time (two hours per day). From this table it is also evident that only one of the participants had ever spoken to the women with intellectual disabilities about sexuality education before. Two thought that the women with intellectual disabilities had not yet been exposed to sexuality education previously, while two thought they had been exposed and one was unsure. Only one participant was aware that the residential care facility had an existing sexuality policy, while two were unsure, and two believed that it did not have a policy. Despite this, four participants supported a sexuality policy, with one being unsure.

5.6.4 General Data Collection Procedures

The training date was scheduled for a Tuesday, as Monday is regarded a “clinic day”. Pilot Study 2 took place from 9:00 to 11:30. Participants were enthusiastic and eager to participate in Pilot Study 2 as they had enjoyed participating in Pilot Study 1. The fact that this pilot study comprised both participants who had previously been trained as well as new participants provided a good basis for Pilot Study 2. Previous participants valued the fact that their input was regarded as important and acknowledged the change in the training programme. This positive attitude impacted favourably on the two new participants. The three previous participants were also able to judge how the new Theme 2 compared to the other themes in the training programme.

5.6.5 Material

Chapter 4 shows the new Theme 2 as it was changed following Pilot Study 1.

Table 5.7: Objectives, materials and equipment, procedures, results and recommendations following Pilot Study 2

Rationale	Materials & Equipment	Procedure	Results	Recommendations
To evaluate Theme 2 of the sexuality and relationship education training programme: Privacy and appropriate conversations				
To evaluate the effectiveness of the <i>icebreaker</i> for setting the group at ease, practising turn-taking, group collaboration as a problem-solving skill by participants, each contributing their own skills to the exercise.	A5 cardboard activity cut in half Koki pens Pictures of happy faces; pictures of sad faces	The trainer gave each participant two pieces of A5 cardboard, one labelled "happy" secrets and one labelled "unhappy" secrets	The trainer had to explain comprehensively to the participants what was meant by a "happy" secret and an "unhappy" secret. The researcher had to provide the participants with practical examples of "happy" and "unhappy" secrets. One of the participants gave an example of having a surprise baby shower for her friend before the activity could commence. Each participant had to write down a "happy" secret on the cardboard labelled "happy" secret and an "unhappy" secret on the cardboard labelled "unhappy" secret.	This new icebreaker will remain for the main study for the enhancement and understanding of "happy" and "unhappy" secrets.
To determine the appropriateness of <i>Social Story 2</i> aimed at the understanding that there are happy secrets such as a surprise birthday party held for someone who knows nothing about it. Unhappy secrets are when people want to take advantage of someone and ask you to keep the secrets about the sexual things they do that can be harmful to others.	Social Story 2: Happy and unhappy secrets Proxima projector Laptop	Social Story 2 was read to the participants. While reading the story, the trainer simultaneously pointed to the pictures on the PowerPoint slides. In addition, each caregiver also received their own printed new version of Social Story 2.	After reading Social Story 2, the trainer asked for comments from the participants related to the appropriateness of the content. Participants agreed that it was suitable for the following reasons: (i) the women with intellectual disabilities do have difficulty in being discreet in public or confidential conversations; (ii) women with intellectual disabilities find it difficult to understand the boundaries between public and private related topics, which is needed to be socially appropriate when having conversations; (iii) women with intellectual disabilities have difficulty with being discreet related to other issues beyond sexuality. For example, they may ask adults their age or strange men if they are married.	In an attempt to teach women with intellectual disabilities how to be more discreet within social contexts, it is often necessary to enhance their understanding of the concepts public and private, labelling specific topics as either private and confidential, thereby enhancing their ability to be socially appropriate within their immediate environment. Social Story 2 focuses on the importance of social appropriateness related to privacy and confidentiality related to "happy" and "unhappy" secrets.
To gauge the appropriateness of the <i>activity</i> included in Theme 2 "Dare to share".	Group activity: "dare to share" Wigs Hats	The activity took place in an informal relaxed group format through role-play. Participants were asked to volunteer and those that did could choose a	"Dare to share activity" with the following questions included: "Who is your favourite singer?" "Do you sometimes eat your dessert before your food?"	It is recommended that some of the questions be changed to link to "happy" and "unhappy" secrets for example, "Have you been married before?" or "Have you ever been

Rationale	Materials & Equipment	Procedure	Results	Recommendations
		hat or wig.	<p>“What is your favourite programme on television?”</p> <p>“Who is your role model?”</p> <p>“Do you snore?”</p> <p>“Do you sing in the bath/shower?”</p> <p>“Do you talk to yourself?”</p> <p>The participants were very spontaneous in participating in this activity.</p>	humiliated in public?” All the questions in Theme 2 should change for the main data collection.
To appraise the effectiveness of the <i>cool-down activity</i> in ending the session in a relaxing and fun way.	Role-play	Participants had to role-play a character of their choice and the rest of the group had to guess who they are or what they were doing in the form of a group discussion.	<p>Participants initially did not understand what “happy” and “unhappy” secrets meant. However, after this was clarified by providing examples, the rest of the activity worked well. The researcher told the group that they were going to role-play but not as themselves. The participants were encouraged to think of names for their characters to help depersonalise themes and encourage the group not to personally identify with doing something bad or feeling angry. Each participant had to pair with another participant. They were told by the researcher and that they were going to do something about saying “no”. Each participant could choose from several items (wigs and hats) that they identified with to portray their character. For example, two participants role-played two friends, the one addicted to drugs, offering the other participant to use drugs with her and she had to say “no!” Another example is where two participants role-played mother and daughter. The mother tried to force her daughter to go for an abortion and the daughter said “no!”</p>	It is recommended that this activity be expanded with an exercise about “happy” and “unhappy” secrets”. A5 size coloured paper/cardboard will be used. Each participant will receive two pieces of A5 size paper/cardboard one labelled “happy” secret and the other cardboard labelled “unhappy” secret. The participants need to write on each of their cards what they perceive as a “happy” secret and an “unhappy” secret and then share it with the group in a discussion format.

5.6.6 Summary

Following Pilot Study 2, only minor recommendations for change were suggested to the group activity “Dare to Share”. In general, the participants rated this activity as more appropriate and relevant than the previous Theme 2. Following Pilot Study 1, major changes were recommended to the adapted measuring instrument.

5.7 PILOT STUDY 3

5.7.1 Aims

The overarching aim of Pilot Study 3 was to evaluate and test the applicability of the measuring instrument and the concepts used to test knowledge and attitudes about sexuality related issues of caregivers working with women with intellectual disabilities. This was a result from Pilot Study 1, which suggested major changes to the instrument. As it was not possible to redo the instrument on the same group of participants due to the fact that they had recently completed it and were thus familiar with the content, Pilot study 3 was planned at a new venue.

5.7.2 Description of Setting

The same residential care facility within the Gauteng area that was used to conduct Focus Group 2 was used for Pilot Study 3. This was a comparable but different setting to the one used for Pilot Study 1 and 2.

5.7.3 Participants

Although the same residential care facility that was used for Focus Group 2 was also used for Pilot 3, none of the participants who participated in Pilot Study 3 were included in Focus Group 2. All of the participants met the selection criteria. The reason for selecting new participants was to ensure that they were novel to the measuring instrument and that they had not been influenced by either the training or by interaction with other participants who had been trained.

In Table 5.8 the biographical information of the participants from Pilot Study 3 are included.

Table 5.8 Biographical information of participants in Pilot 3 (N=10)

Participant	P3.1	P3.2	P3.3	P3.4	P3.5	P3.6	P3.7	P3.8	P3.9	P3.10
Gender	Female	Male	Male	Female	Female	Female	Female	Female	Female	Female
Age	40 years	25 years	24 years	37 years	46 years	34 years	47 years	40 years	63 years	33 years
Home language	Afrikaans	English Afrikaans	Setswana	Setswana	English Afrikaans Setswana	Afrikaans	Afrikaans	Setswana	English Afrikaans	Setswana
Religious affiliation	Christian	Christian	Christian	Christian	Christian	Christian	Christian	O.A.C	Christian	Christian
Church attendance	Once a week	Once a month	Special occasions	Once a month	Once a month	Once a week	Once a week	Once a week	Once a month	Once a month
Years working at the residential care facility	8 years	4 years	4 months	2 years	3 years	10 years	9 years	9 years	5 years	6 years
Total hours working per day	8 hours	4 hours	8 hours	8 hours	6 hours	6 hours	8 hours	8 hours	8 hours	8 hours
Spoken about sexuality to women	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes
Awareness of women exposed to sexuality education previously	Yes	Yes	Unsure	Unsure	No	Yes	Yes	Yes	Yes	Unsure
Awareness of existing sexuality policy at the facility	Unsure	Yes	Unsure	Yes	Yes	Yes	Yes	Yes	Yes	Unsure
Support of sexuality policy	Yes	Yes	Unsure	Yes	Yes	Yes	Yes	Yes	Yes	No

From the table above it is clear that six of the participants were aware that the women with intellectual disabilities had been exposed to sexuality education before. Eight out of ten participants supported a sexuality policy. In addition, nine out of the ten participants had previously spoken to women with intellectual disabilities about sexuality.

5.7.4 Procedures

The date was confirmed with the social worker for a Thursday. Ten caregivers participated in completing the new measuring instrument.

5.7.5 Material

The measuring instrument was adapted, rephrased and refined following Pilot Study 1. Section A (the biographical info) remained exactly the same (see Section A), and is therefore not described again. However, the new instrument used a binary scale (true/false) and the question formulation was also changed to accommodate the new Theme 2, as well as to incorporate the suggested changes from Pilot Study 1. Before the pilot, a panel of ten experts in the field of AAC and disability evaluated the face validity of the new instrument and suggested changes. Suggestions were made related to consistency of terminology, heightened focus (women with intellectual disabilities) and reducing sentence length. Changes were categorised into refining, rephrasing and adapting, according to the extensiveness of the changes required. Refining was defined as adding only one or two words in order to make the intent of the question clearer, for example, adding *“women with intellectual disabilities”* or the word *“should”*. Rephrasing referred to the re-articulation of questions so that the main intent of the question remained the same, but that the wording of the question changed considerably to also enhance the meaning of the question. Adapting referred to questions which were modified to be able to fit into the specific theme. A description of the new Section B is given in Table 5.9.

Table 5.9: Adaptations made to Section B of the measuring instrument after the expert panel review and pilot study

Quest nr	Question area	Initial question formulation	New question formulation	Answer	Type of change required and justification
Section B: Current knowledge and attitudes					
This section contains 39 questions about appropriate and inappropriate touching, privacy and appropriate conversations, romantic relationships and sexuality education. These aspects were directly related to the four themes covered in the aSeRT training. Knowledge, attitudes and behaviour related to sexuality will affect how caregivers react to specific situations (Jorisson, 2008) and hence form the backbone of this training. These questions were all answered in a binary (true or false) format.					
Old 12 New 12	Appropriate & inappropriate touching	Women with intellectual disabilities know that there are different ways to touch strangers and familiar people.	Women with intellectual disabilities should know that there are different ways to touch strangers and familiar people.	True	Refining: The word <i>“should”</i> was added to make the intention of the question clearer, so that the caregivers knew who was referred to.

Quest nr	Question area	Initial question formulation	New question formulation	Answer	Type of change required and justification
Old 13 New 13	Appropriate & inappropriate touching	It is important to pick up non-verbal cues from others.	It is important for women with intellectual disabilities to understand non-verbal behaviour from other people.	True	Rephrasing: The question was changed to enhance understanding and be more specific as to who the two different parties are that are being referred to.
Old 14 New 14	Appropriate & inappropriate touching	Women with intellectual disabilities have an increased need for touch and affection.	Women with intellectual have a great need for touch than women without intellectual disabilities.	False	Refining: This question was changed to make the intent clearer by describing "increased need" as a "greater need".
Old 15 New 15	Appropriate & inappropriate touching	A handshake is an appropriate way to greet an authority figure.	Women with intellectual disabilities should know an appropriate strategy to greet a stranger, for example, a handshake.	True	Rephrasing: The question was changed to more clearly describe who is referred to and also what is meant by the greeting example.
Old 16 New 16	Different types of relationships	Romantic touching is appropriate between caregivers and the women they care for.	Romantic touching is not appropriate between caregivers and the women with intellectual disabilities they care for.	False	Rephrasing: The question was changed from a positive statement (which is typically the preferred format in questionnaires) to a negative statement in order to not perpetuate this myth.
Old 17 New 17	Privacy and appropriate conversations	There are different ways to behave in public and private places.	Women with intellectual disabilities have difficulty understanding the boundaries between "public" and "private".	True	Rephrasing: Emphasising the difficulty that women with intellectual disabilities have with understanding appropriate social boundaries.
Old 18 New 18	Privacy and appropriate conversations	Because women with intellectual disabilities live in isolation their bodies do not always give them signals when they are unsafe.	Women with intellectual disabilities do not know when they are unsafe in a relationship.	True	Rephrasing: This statement was reworded in order to make it shorter and more to the point so that the intent is clear.
Old 19 New 19	Appropriate & inappropriate touching	Women with intellectual disabilities need to be aware that their bodies belong to themselves.	Women with intellectual disabilities like to be touched by anybody.	False	Adapting: This question was shortened and redirected to be closer aligned with the training content.
Old 20 New 20	Privacy and appropriate conversations	Teaching privacy concepts can help women with intellectual disabilities understand the rules of society.	Women with intellectual disabilities should know how to start appropriate conversations.	True	Adapting: This question was adapted in order to bring it more in line with the training content and to provide an example of what it would mean to "understand the rules of society".
Old 21 New 21	Privacy and appropriate conversations	Sexuality almost always involves the idea of "public" and "private".	Women with intellectual disabilities should understand that some secrets make them "happy" and some	True	Adapting: This question was re-written in order to reflect the new theme that was included namely what privacy would mean in a conversation as opposed to

Quest nr	Question area	Initial question formulation	New question formulation	Answer	Type of change required and justification
			secrets make them "unhappy".		in a place.
Old 22 New 22	Privacy and appropriate conversations	Teaching women about relationships involves teaching them about social skills.	Caregivers should teach women with intellectual disabilities how to label new information as "public" and "private".	True	Adapting: To reflect the new theme, this question underscored the importance of knowing how to judge different types of information in conversations.
Old 23 New 23	Privacy and appropriate conversations	In relationships it is important how to greet and interact appropriately in different situations.	Women with intellectual disabilities should know that people who want to take advantage of them will ask them to keep secrets about sexual things.	True	Adapting: To reflect the new theme, women with intellectual disabilities need to be taught what a secret is that can harm them and how to say "no" when they feel uncomfortable with not telling anyone.
Old 24 New 24	Romantic relationships	Caregivers who work in residential care facilities need to teach women how to have healthy relationships with other.	Teaching women with intellectual disabilities involves teaching them about social skills.	True	Adapting: This question had to be changed to reflect the new "romantic relationship theme" which replaced the earlier "dating" theme.
Old 25 New 25	Privacy and appropriate conversations	Caregivers may have sexual feelings for the women they take care of.	In relationships it is important how to greet appropriately in different situations.	True	Adapting Privacy was changed to reflect privacy in conversations and not in places, as that was more appropriate in the context.
Old 26 New 26	Different types of relationships	Caregivers need to teach women the difference between healthy and unhealthy relationships.	Caregivers are people who get paid to help and assist the women with intellectual disabilities they take care of.	True	Adapting: The question was changed to more clearly differentiate the different types of relationships and to specifically highlight what was meant by "caregivers".
Old 27 New 27	Different types of relationships	Dating is a planned activity that can help women to know how to start appropriate conversations.	Caregivers may have sexual feelings for the women they take care of.	False	Adapting: This question was changed to more clearly reflect the new theme that was added. All the references to "dating" in questions were removed.
Old 28 New 28	Different types of relationships	It is okay for caregivers to touch women in a sexual way.	Caregivers need to teach women with intellectual disabilities the difference between good and bad relationships.	True	Rephrasing: The general intent of this question remained the same, but the wording was changed in order to make it clearer and more intelligible.
New 29 Old 29	Different types of relationships	It is important that the values and the natural progression of dating are addressed with women with intellectual disabilities	Women with intellectual disabilities should know that the person they are interested in should not be related to them.	True	Adapting: This question was changed to reflect the new theme "different types of relationships" as Pilot Study 1 revealed that dating was not an appropriate activity for the population.
Old 30	Appropriate &	Romantic	It is okay for caregivers	False	Adapting:

Quest nr	Question area	Initial question formulation	New question formulation	Answer	Type of change required and justification
New 30	inappropriate touching	relationships are when two people have sexual feelings for each other.	to touch women in a sexual way.		This question was changed to reflect the new theme. Throughout "intimate touching" was replaced with "touching in a sexual way".
Old 31 New 31	Romantic relationships	Teaching women to have conversations can help them feel more comfortable in their relationships.	Women with intellectual disabilities should be able to have relationships with others.	True	Adapting: This question more closely resembled the content of the new theme. Aligning the measuring instrument items with the aSeRT training is essential.
Old 32 New 32	Different types of relationships	Sexuality education should be taught to women with intellectual disabilities.	Romantic relationships are when two people have sexual feelings for each other.	True	Adapting This question reflects the crux of the new theme which focused on romantic relationships.
New 33	Sexuality education	None.	Sexuality education will assist women with intellectual disabilities to make more responsible choices.	True	New question A new question was added to the "sexuality education section" in order to ensure that the number of questions in that section was similar to the other sections.
New 34	Romantic relationships	None.	It is important that the natural progression of romantic relationships is discussed with women with intellectual disabilities.	True	New question This question was added for the new theme "romantic relationships" in order to ensure an appropriate weighting of this theme in relation to the other themes.
Old 33 New 36	Different types of relationships	Sexuality education will empower women to make responsible choices.	Sexuality education will empower women to make responsible choices.	True	This question remained the same, but the order of the question changed.
Old 34 New 37	Romantic relationships	A sexuality education programme will result in more sexuality activity.	A sexuality education programme will result in more sexuality activity.	True	This question remained the same, but the order of the question changed.
Old 35 New 38	Sexuality education	Women with intellectual disabilities' understanding of their sexuality are important for their self-image.	Women with intellectual disabilities' understanding of their sexuality are important for their self-image.	True	This question remained the same, but the order of the question changed.
Old 36 New 39	Sexuality education	Women with intellectual disabilities are sterile.	Women with intellectual disabilities are sterile.	True	This question remained the same, but the order of the question changed.
Old 37 New 40	Sexuality education	Women with intellectual disabilities are oversexed.	Women with intellectual disabilities are oversexed.	True	This question remained the same, but the order of the question changed.
Old 38 New 41	Sexuality education	Women with intellectual disabilities are more vulnerable to sexual abuse and exploitation than	Women with intellectual disabilities are more vulnerable to sexual abuse and exploitation than women who do not	True	This question remained the same, but the order of the question changed.

Quest nr	Question area	Initial question formulation	New question formulation	Answer	Type of change required and justification
		women who do not have intellectual disabilities.	have intellectual disabilities.		
Old 39 New 42	Sexuality education	Women with intellectual disabilities often engage in sexual behaviour.	Women with intellectual disabilities often engage in sexual behaviour.	False	This question remained the same, but the order of the question changed.
Old 40 New 43	Appropriate and inappropriate touching	Women with intellectual disabilities are asexual (they have no sexual needs).	Women with intellectual disabilities are asexual (they have no sexual needs).	True	This question remained the same, but the order of the question changed.
Old 41 New 44	Sexuality education	Women with intellectual disabilities experience puberty later than their peers.	Women with intellectual disabilities experience puberty later than their peers.	True	This question remained the same, but the order of the question changed.
Old 42 New 45	Sexuality knowledge	Sexuality involves social aspects.	Sexuality involves social aspects.	False	This question remained the same, but the order of the question changed.
Old 43 New 48	Different types of relationships	Sexuality involves relational aspects.	Sexuality involves having a relationship with someone.	False	Rephrasing to make the intent clearer and the order of the question changed.
Old 44 New 47	Different types of relationships	Touch is an essential part of being human.	Touch is an essential part of being human.	False	This question remained the same, but the order of the question changed.

Table 5.10 showed the new measuring instrument following recommendations by the expert panel and Pilot Study 1. It specifically outlined which three questions were refined, which seven rephrased, and which 14 adapted. It also shows the two new questions which were included, as well as the 12 questions which were re-numbered. Following this process, the new measuring instrument was tested by means of Pilot Study 3.

5.7.5.1 Objectives, results and recommendations following Pilot 3

The objectives, results and recommendations made after Pilot Study 3 are given in Table 5.10.

Table 5.10: Objectives, materials and equipment, procedures, results and recommendations following Pilot Study 3

TO EVALUATE THE MEASURING INSTRUMENT WITH REGARDS TO THE FOLLOWING OBJECTIVES:				
Rationale	Material & equipment	Procedures	Results	Recommendations
To determine the appropriateness of the terminology used in the measuring instrument	Measuring instrument	The participants were asked to complete the measuring instrument. The trainer was available throughout.	New terminology was understood and questions asked related to the terminology used in the measuring instrument	The questions will remain the same for the main data collection.
To determine if the instructions were clear and easy to follow	Measuring instrument	The trainer was available at all times to address any uncertainties.	Questions were asked about variable numbers. It was explained that it was for office use only.	The instructions will remain the same for the main study.
To determine if the time it took to read and answer the questions was enough	Measuring instrument; timer	Participants completed the measuring instrument without discussing questions with each other.	The average time it took to complete questionnaires was 90 minutes.	The trainer should check the questionnaire in the main study to ensure that all the questions were answered after completion by the participants, thereby avoiding "missing data".
Appropriateness of the rating scale	Measuring instrument	A binary scale was used for the newly developed measuring instrument (True/False).	The choice of a binary scale ensured that the participants had a choice between true or false. This eliminated the "unsure" choice.	The choice of using a binary scale will remain the same for the main study.
Appropriateness of the content of the questions in Section B	Measuring instrument; Section B participants	Participants completed Section B of the measuring instrument by either choosing true or false when responding to the questions.	Answers provided were logical and as expected. The inclusion of an expert panel before this pilot impacted positively on the appropriateness of the content.	The instrument as used in Pilot Study 3 will be used in its current format for the main study.

5.8 MAIN STUDY

First participants are described according to the criteria and then according to their biographical data. Next, the data collection and procedures are discussed, which includes a description of the ethical considerations adhered to. Finally, data analysis is described.

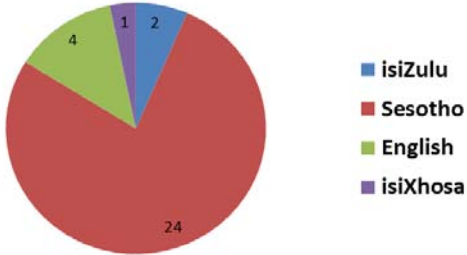
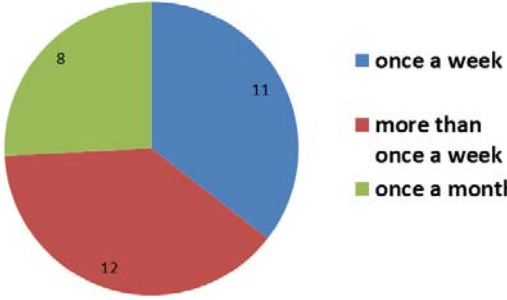
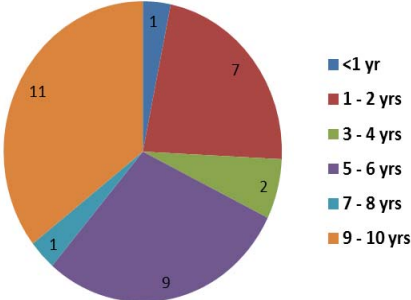
5.8.1 Participant Selection and Description

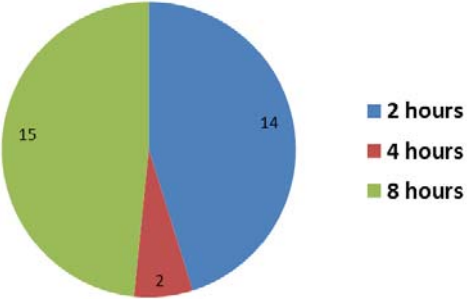
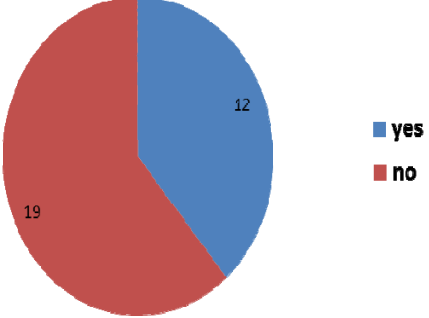
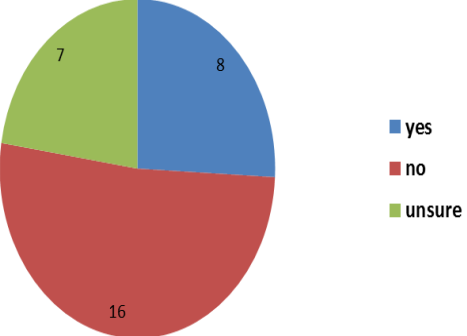
All participants had to meet the following criteria to be able to participate in the study:

- i) Be female, as women with intellectual disability are vulnerable to sexual abuse and exploitation (Bornman, 2014; Forchuck et al., 1995).
- ii) Interact with women with intellectual disabilities on a daily basis between two and eight hours, as the total amount of time spent with women with intellectual disabilities impacts on their knowledge and attitudes because time shapes perceptions (Bazzo et al., 2007).
- iii) Be working with women with intellectual disabilities at a residential care facility, as perceptions and attitudes filter down over time (Bouman et al., 2007; Karellou, 2003).

The selection criteria resulted in a total of 31 participants being included in the main study. All were female, with an average age of 40 years old (ST 9.51). The youngest participant was 23 years old, while the oldest was 59 years old. Regarding their experience of working at the specific residential care facility it was reported that they worked for an average of five years six months (ST 3.17). The participants with the shortest amount of experience was 2.5 months, while the one with the most experience had been working for ten years at this facility. The question about their working hours per day, which relates directly to working with the women with intellectual disabilities, showed an average of five hours per day (ST 3.0), with the shortest being two hours per day and the longest eight hours per day. The remainder of the participants' descriptive information is provided in Table 5.11.

Table 5.11: Descriptive information of participants (N=31)

Description	Results (N=31)														
<p>First Language 24 participants spoke Sesotho. The three Nguni language speakers comprised two isiZulu and one isiXhosa speaker. The four English speakers all stated that they speak English in addition to an African language at home, with two speaking English and Sesotho, one speaking English and Setswana and one speaking English and isiZulu.</p>	 <table border="1"> <caption>First Language Data</caption> <thead> <tr> <th>Language</th> <th>Count</th> </tr> </thead> <tbody> <tr> <td>isiZulu</td> <td>2</td> </tr> <tr> <td>Sesotho</td> <td>24</td> </tr> <tr> <td>English</td> <td>4</td> </tr> <tr> <td>isiXhosa</td> <td>1</td> </tr> </tbody> </table>	Language	Count	isiZulu	2	Sesotho	24	English	4	isiXhosa	1				
Language	Count														
isiZulu	2														
Sesotho	24														
English	4														
isiXhosa	1														
<p>Religion and church attendance All 31 participants indicated that they were Christians. However, their church attendance varied.</p>	 <table border="1"> <caption>Church Attendance Data</caption> <thead> <tr> <th>Attendance</th> <th>Count</th> </tr> </thead> <tbody> <tr> <td>once a week</td> <td>11</td> </tr> <tr> <td>more than once a week</td> <td>12</td> </tr> <tr> <td>once a month</td> <td>8</td> </tr> </tbody> </table>	Attendance	Count	once a week	11	more than once a week	12	once a month	8						
Attendance	Count														
once a week	11														
more than once a week	12														
once a month	8														
<p>Years working at the Centre One participant had only been working at the centre for less than a year, while 21 of the participants had been working at the facility for five years or more, with the majority of them (11) working for nine years or more.</p>	 <table border="1"> <caption>Years working at the Centre Data</caption> <thead> <tr> <th>Years</th> <th>Count</th> </tr> </thead> <tbody> <tr> <td><1 yr</td> <td>1</td> </tr> <tr> <td>1 - 2 yrs</td> <td>7</td> </tr> <tr> <td>3 - 4 yrs</td> <td>2</td> </tr> <tr> <td>5 - 6 yrs</td> <td>9</td> </tr> <tr> <td>7 - 8 yrs</td> <td>1</td> </tr> <tr> <td>9 - 10 yrs</td> <td>11</td> </tr> </tbody> </table>	Years	Count	<1 yr	1	1 - 2 yrs	7	3 - 4 yrs	2	5 - 6 yrs	9	7 - 8 yrs	1	9 - 10 yrs	11
Years	Count														
<1 yr	1														
1 - 2 yrs	7														
3 - 4 yrs	2														
5 - 6 yrs	9														
7 - 8 yrs	1														
9 - 10 yrs	11														

<p>Hours working per day Fifteen of the participants worked eight hours per day with women with intellectual disabilities at the facility, while 14 worked only two hours per day.</p>	 <p> ■ 2 hours ■ 4 hours ■ 8 hours </p>
<p>Spoken to women about sexuality before Twelve of the participants stated that they had not spoken to the women about sexuality previously, while 19 stated that they had spoken to women previously about sexuality education.</p>	 <p> ■ yes ■ no </p>
<p>Awareness of women being exposed to sexuality training before Sixteen of the participants stated that they were not aware of any women being exposed to sexuality training previously, while seven indicated that they were unsure if the women they took care of had been exposed to sexuality education before. Only eight participants indicated that they were aware of the fact that the women in their care had been exposed to sexuality education before.</p>	 <p> ■ yes ■ no ■ unsure </p>

<p>Awareness of existing sexuality policy Most of the participants (13) were aware of an existing sexuality policy at the residential care facility they worked at. However, an equal number (nine each) were not aware of existing policies and were unsure of the existence of a policy about sexuality pertaining to the women in their care.</p>	 <table border="1"> <thead> <tr> <th>Response</th> <th>Count</th> </tr> </thead> <tbody> <tr> <td>yes</td> <td>13</td> </tr> <tr> <td>no</td> <td>9</td> </tr> <tr> <td>unsure</td> <td>9</td> </tr> </tbody> </table>	Response	Count	yes	13	no	9	unsure	9
Response	Count								
yes	13								
no	9								
unsure	9								
<p>In support of sexuality policy The majority of caregivers (28) supported the implementation of a sexuality policy at their facility. Only one participant did not support a sexuality policy and two participants were unsure of whether they were in support of such a policy or not.</p>	 <table border="1"> <thead> <tr> <th>Response</th> <th>Count</th> </tr> </thead> <tbody> <tr> <td>yes</td> <td>28</td> </tr> <tr> <td>no</td> <td>1</td> </tr> <tr> <td>unsure</td> <td>2</td> </tr> </tbody> </table>	Response	Count	yes	28	no	1	unsure	2
Response	Count								
yes	28								
no	1								
unsure	2								

From the above table it is clear that the participants were all well suited to participate in the training.

5.8.2 General Data Collection and Procedures

The general data collection procedures commenced with the following steps:

The regional director of the Social Development Network in a specific peri-urban area in the Gauteng area was contacted telephonically as she had links with specific residential care facilities for women with intellectual disabilities. She was briefly informed about the purpose of the research and a meeting was scheduled for the following day to give more detail about the study.

A meeting was held where an information letter was given to the regional director to describe the purpose, procedure and participant selection criteria. The director was also provided with the Sexuality and Relationship Training manual as well as a training pack. A brief discussion was held about the content of the training programme as well as the themes. The director agreed to assist with participant recruitment by phoning potential participants.

The regional director contacted all the residential care facilities in the region, informing them of the training and extending an invitation to all relevant caregivers to participate in the two-day programme.

It was ensured that the venue was conducive for the type of training. The venue was 200 square metres in size, excluding the kitchen and restroom facilities, allowing the researcher to use half of the floor space for theory training and the remainder for activities such as icebreakers, role-play and cool-down activities. The tables and chairs were positioned in a u-shape for participants to be able to have a clear view of the researcher, the PowerPoint slides and to interact with one another during feedback sessions.

Transport was arranged and provided to and from the venue for all participants. On the morning of the first day of training, a total of 32 participants arrived. The researcher explained the primary aim of the study to all participants.

The measuring instrument was administered to the participants to determine their existing attitudes and knowledge related to the sexuality of women with intellectual disabilities. The participants were made aware of: (i) the relaxed and non-threatening environment through the use of icebreakers; (ii) group participation through activities; (iii) the sensitivity of the topic through use of appropriate terminology; and (iv) the need to ensure that all participants received the same training, made possible through the provision of a training manual. One theme per session was addressed for 90 minutes per session, over the two days.

The attendance register showed that only 31 of the 32 participants returned for the second day of training, (thus an attrition rate of one). Only the data of the 31 participants who attended both days of training was included in the analysis and discussion. On conclusion of the training, the measuring instrument was completed using complete birth dates (year, month, day) as identity markers as in the pre-test to ensure

that the same participants completed the pre- and post-test. In addition, all participants completed the training evaluation questionnaire at the end of the second day.

The written informed consent indicated the information that would be disclosed, the purpose of the disclosures, and to whom it would be disclosed (see Appendix L and M for written consent letters used in this study). McCarthy (1998, p. 142) states that it is generally accepted in the literature that “the more sensitive the topic, the greater the need for ascertaining truly informed consent”. The researcher had to reassure the participants that the information obtained from the study would be kept confidential and that their names and other identifying demographics would not be used in the dissemination of the research findings (McCarthy, 1999). All participants were assigned a participant number. The participants were not subjected to any risks. The only discomfort that they might have experienced while participating in this study was the sacrifice of their own free time. The participants were informed that they had the right to withdraw from the study at any given time. Should they decide to withdraw, their decision to do so would in no way penalise them.

The research results will be made available upon request following the completion of the study. The research data will be stored both as hard copy and in electronic format at the Centre for AAC at the University of Pretoria for 15 years.

5.8.3 Material and Equipment

All four items discussed in Chapter 5 were used, including the aSeRT manual, the final measuring instrument as described in Table 5.9, the training packs and the training evaluation questionnaire. All of the items had undergone rigorous pilot testing to ensure suitability and relevance for the main study.

i) The aSeRT Training Manual

The overarching aim of the aSeRT training manual is to offer a practical introduction to sexuality and relationship training in order to equip caregivers for training women with intellectual disabilities. Using a manual also ensured that all participants received the same training. The final manual is included in Chapter 4.

ii) Measuring Instrument

The aim of the measuring instrument is to measure the knowledge and attitudes of caregivers who take care of women with intellectual disabilities related to sexuality issues, before and after training. The final measuring instrument used in the main study following the expert panel review and pilot studies is included in Appendix F.

iii) Training Packs

Each participant received a training pack as described in 5.4.2.

iv) Training Evaluation Questionnaire

Each participant completed a training evaluation questionnaire as described in Table 5.3 and shown in Appendix G.

v) Equipment

The equipment used for the training of the caregivers, data collection and analysis consisted of a laptop and a Proxima projector, a flipchart and pens.

5.8.4 Data Analysis and Statistical Procedures

All the data were documented on the measuring instrument (pre-and post-training). Similarly, participants' responses were recorded on the training evaluation questionnaire. A pre-designed column marked *“for official use”* was placed on the right-hand side of both the measuring instrument and the post-training questionnaire for encoding the raw data. The researcher encoded all the raw data according to specific data definitions. Subsequently, data was computerised for statistical analysis with the SAS programme (Steyn, Smit, Du Toit & Strasheim, 2000). The data were then analysed using a variety of statistical

procedures, including descriptive statistics, data reliability measures and inferential statistics – both parametric and not-parametric tests. Each of these will be discussed in turn below.

i) Descriptive Statistics

Discreet frequency distribution counts were calculated for all the variables, which implied that all variable values were listed and counted each time they occurred (Maree, 2011). Percentages of different variables, for example, first language, were determined and compared. Mean scores and standard deviations were calculated when relevant to provide information on the spread of the distribution. The results are displayed with pi-charts and histograms. Tables are used in cases where a summary of data is required.

ii) Data Reliability Measures

In order to test the internal consistency of the items, the Kuder Richardson 21 formula (KR-21) was used as it is applicable to measuring instruments that have a binary scoring system such as the one used in this study, which had a true-false answer type (Kerlinger & Lee, 2000).

iii) Inferential Statistics: Parametric Tests

The paired-t test was used to compare the means, pre-training and post-training in order to determine whether the differences between the means was significant due to change (Sarantakos, 2013).

iv) Inferential Statistics: Non-Parametric

As no assumptions were made regarding the form of the sample population or the values of the distribution, in other words, normality of the distribution, non-parametric statistics were used to test the significance of the findings (Kerlinger & Lee, 2000). Two different non-parametric tests were used:

- The Wilcoxon rank sum test was used to compare the two samples (before and after training), which were drawn independently (Steyn et al., 2000). The Wilcoxon rank sum test is similar to the t-test (Maree, 2011; Sarantakos, 2013). Variables are compared in a single sample, such as a pre-test and post-test. The test is performed based on one variable, namely the difference between two scores (Maree, 2011). Differences are ordered and ranks are then assigned to them. Hence, the actual values of the differences are not used.
- The Kruskal Wallis test was used as a simple and effective one-way analysis of variance (Kerlinger & Lee, 2000).

5.8.5 Ethical Considerations

There are ethics to which researchers need to adhere (Sarantakos, 2013). Before proceeding with this study, ethics approval was obtained from the Research Committee of the University's Faculty of Humanities (Appendix N). In this study attention was specifically given to four different ethical principles. In the first place, the principle of voluntary participation was adhered to (McMillan & Schumacher, 2010). This meant that the researcher did not pressurise any potential participants into participating by attempting to convince them to take part in the study and she clearly explained that should any participants feel any discomfort or resistance related to the study, for example, during the focus groups or training, they could stop or withdraw at any time without any negative consequences. The nature of the training focused on building rapport and trust, for example, through the use of icebreakers and cool-down activities (Stanchfield, 2013). This resulted in a relaxed atmosphere conducive to training, which possibly contributed to the fact that participants wanted to engage and be part of the training.

The second principle that was considered was the principle of informed consent. Ethics approval from the relevant authorities (Appendices H; J; L and M) was also obtained in the form of consent letters. This includes informing participants regarding the main aim and sub-aims, as well as the nature of the study and potential risks, including potential physical or mental stress (Campbell, Vasques, Behnke & Kinscherff, 2010). Due to the sensitive nature of the topic, this principle was particularly relevant for the present study. Failure to explain all relevant aspects of the study to the participants before they agreed to participate would lead to a violation of this principle (Sarantakos, 2013). The consent letter was accompanied by a

detailed information letter outlining all these aspects, as well as the aim and sub-aims of the study. Participants were clearly instructed and understood the researcher's expectations. Participants confirmed voluntary participation in the form of a signed consent letter. This letter also offered them a summary of the study results and conclusions (see Appendix M).

The third principle focused on data confidentiality and anonymity. Due to the pre-test post-test design used in Phase 2 of this study, anonymity could not be promised to participants, only confidentiality. All data were coded (using participant numbers rather than names), and all identifying information was removed from the thesis in order to respect the participants' privacy.

In the fourth instance, the principle of veracity, which focuses on honesty, trust and accuracy, was obeyed. This was done by including objective techniques, for example, using principles of adult learning during the training phases, and obeying ethical and/or professional research standards, for example, by avoiding fabrication, falsifying or concealing data (Sarantakos, 2013). The limitations of the study are described in Chapter 7. Throughout this study, a valid research design was utilised, which included relevant theory, methods and prior findings. Appropriate credit was awarded for the work of scholars in the field through the correct use of referencing. The input of participants was acknowledged in the form of certificates (Appendix O). Throughout the study, the researcher ensured her own independence and impartiality, and clearly stated throughout all of the research phases (development and training) that there were no conflicts of interest or partiality.

5.9 SUMMARY

This chapter described the methodology and material used in this study. The aims and sub-aims were presented, followed by a description of the research design. The three pilot studies each with a unique focus and their results and recommendations were discussed. The criteria for participant selection and material used, such as the training packs used in the research, were presented. The biographical information of the participants was visually presented and discussed. This was followed by a description of procedures for data analysis for the collection of data. Next, the procedures for data analysis were outlined

to form a basis for the presentation and interpretation of the results. The chapter concluded with a discussion of the ethical principles considered.

CHAPTER 6

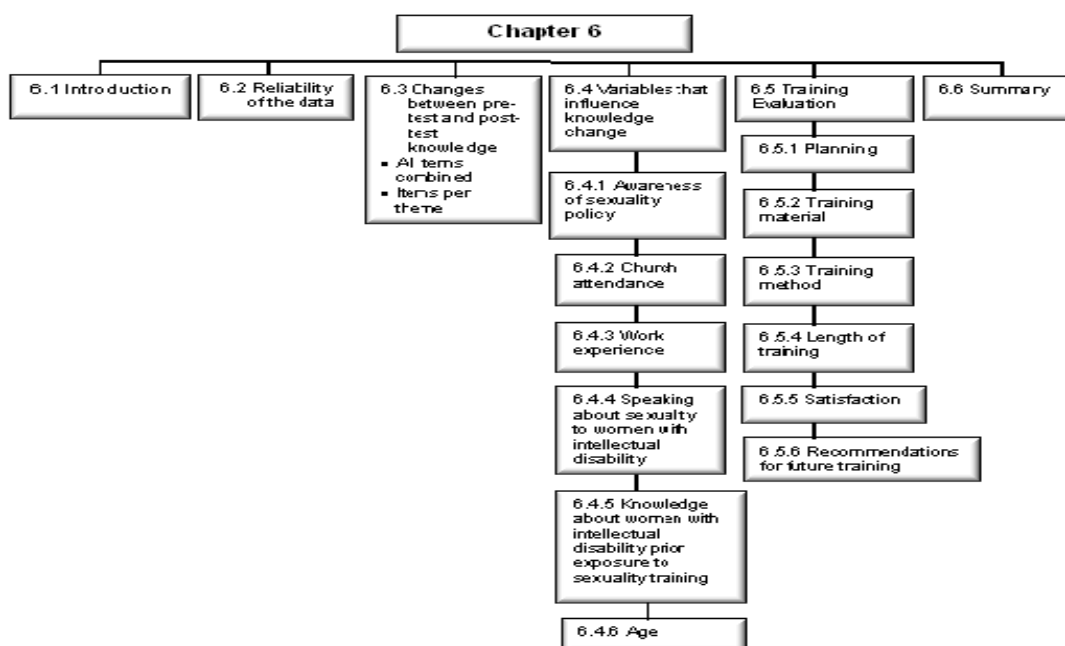
Results and Discussion

6.1 INTRODUCTION

The aim of this chapter is to provide and discuss the results from Phase 3 (the quantitative phase) of the research. It specifically focuses on the last four sub-aims and compares the pre-test and post-test measures of the attitudes and knowledge of caregivers of women with intellectual disabilities regarding sexuality and relationships. It includes the four themes covered in the aSeRT, namely appropriate and inappropriate touching, privacy and appropriate conversations, romantic relationships and different types of relationships, as well as sexuality education. Data are not only organised and analysed but are interpreted so that conclusions can be drawn regarding the effectiveness and usefulness of the aSeRT training in achieving specific outcomes.

Four major components in the description of the results are important. Firstly, issues pertaining to reliability are discussed; secondly, the outcomes of the aSeRT training (knowledge and attitudes regarding the four themes) are described. Next, the influence of variables that have been described in the literature as influencing this type of training will be explored; and finally, general comments regarding the training are made, highlighting the strengths and weaknesses of the training. The outline of this chapter is presented schematically in Figure 6.1.

Figure 6.1: Schematic outline of the quantitative results



6.2 RELIABILITY

Reliability is concerned with the consistency, stability and repeatability of the participants' responses as well as the investigator's ability to accurately collect and record information (Sarantakos, 2013). In order to heighten the reliability, certain precautions were built into the data analysis.

The meaning instrument comprised 47 questions, of which 11 were related to biographical data. Of the 36 content-specific questions, 21 questions proved to be reliable following data collection. The Kuder Richardson 20 formula was used to calculate the reliability of the measuring instrument as it consisted of binary questions (correct scored 1 and incorrect scored 0) (Creswell, 2013). First, most questions with low item-total correlations (rit-values lower than 0.30) were removed. The seven that remained were left in to ensure a comparable number of questions across the four themes. The removal of 19 questions with low item-total correlations (rit-values) resulted in a reliability of 0.62. Although the value is lower than the widely accepted value of 0.70, it was decided not to try and obtain a higher value by removing more questions (Foxcroft & Roodt, 2005). The remaining 21 questions were distributed across the four themes, with five questions referring to appropriate and inappropriate touching, two to different types of relationships, four to privacy and appropriate conversations, and four to romantic relationships. The remaining six questions referred to the overall sexuality training methodology used. In Table 6.1, the rit-values of the 21 questions which remained were further analysed. The question area that these covered is also presented.

Table 6.1: The rit-values of the 21 remaining questions

Question number	Question area	rit-value
14	Appropriate and inappropriate touching	0.26
15	Appropriate and inappropriate touching	0.62
16	Different types of relationships	0.36
17	Privacy and appropriate conversations	0.41
20	Privacy and appropriate conversations	0.22
22	Privacy and appropriate conversations	0.17
23	Privacy and appropriate conversations	0.51
26	Different types of relationships	0.26
30	Appropriate and inappropriate touching	0.17
32	Different types of relationships	0.40
33	Different types of relationships	0.40

Question number	Question area	rit-value
34	Different types of relationships	0.42
35	Sexuality education	0.41
36	Sexuality education	0.36
37	Sexuality education	0.47
39	Sexuality education	0.57
41	Sexuality education	0.43
45	Appropriate and inappropriate touching	0.25
46	Different types of relationships	0.54
47	Sexuality education	0.43
48	Appropriate and inappropriate touching	0.28

For the remainder of this chapter, only these 21 questions will be included in the analysis.

6.3 CHANGES OBSERVED BETWEEN PRE- AND POST-TRAINING KNOWLEDGE

The 21 items on the aSeRT binary scale which had reliable rit-values were combined in order to determine the change in the participants' knowledge between pre and post-training, as shown in Table 6.2.

Table 6.2: Change between pre- and post-training for all items combined (N=31)

	Mean	SD	Paired t-test
Pre-training	13.49	2.89	p = 0.0006*
Post-training	15.13	2.43	
Difference	1.65	2.4	

*p≤0.05 indicating statistical significance on the 5% level of confidence

The post-training mean (15.13) was higher than the pre-training mean (13.49), indicating that a positive change had occurred during training. To determine whether this change was statistically significant, a paired t-test was conducted. A p-value of 0.0006 was recorded, indicating a statistically significant difference between the pre-training and the post-training scores (p≤0.05) on the 5% level of confidence. In order to further determine where the exact differences lay according to the themes included in the aSeRT as well as in the broader section on sexuality training, paired t-tests were conducted. T-tests were not performed for the themes appropriate and inappropriate touching, privacy and appropriate conversations and romantic relationships as adequate reliability was not established for the items in these sub-scales. Results are shown in Table 6.3.

Table: 6.3: Change between pre- and post-training for the four themes (N=31)

Theme	Training	Mean	SD	Paired t-test p-value
Appropriate and inappropriate touching Questions 14, 15, 30, 45, 48	Not tested as the sub-scale rit-values did not meet the requirements			--
Privacy and appropriate conversations Questions 17, 20, 22, 23	Not tested as the sub-scale rit-values did not meet the requirements			--
Romantic relationships No questions	Not tested as no rit-values met the requirements			--
Different types of relationship Questions 16, 26, 32, 33, 34, 46	Pre training	4.61	1.65	0.0340
	Post training	5.38	1.08	
	Difference	0.50	1.0	
Sexuality education Questions 35, 36, 37 ,39, 41, 47	Pre training	4.61	1.33	Wilcoxon 0.0001*
	Post training	5.38	0.98	
	Difference	0.58	1.45	

*p≤0.05 indicating statistical significance on the 5% level of confidence

6.4 VARIABLES THAT INFLUENCED CHANGE IN KNOWLEDGE BETWEEN PARTICIPANT'S PRE- AND POST-TRAINING (DIFFERENCE) SCORES

In order to determine which of the variables could have influenced the participants' knowledge leading to the statistically significant difference between the pre- and post-training scores, six variables were tested using either the Wilcoxon test or the Kruskal Wallis test (Foxcroft & Roodt, 2005). These variables include the awareness of the participants regarding the sexuality policy, the frequency with which participants attended church-related activities, the participants' work experience at the facility, whether the participants had spoken to women with intellectual disability about sexuality, their knowledge regarding the women with intellectual disabilities' prior knowledge, and participants' age. The results are shown in Tables 6.4 to 6.9. These tables show the mean scores and the standard deviation (SD) for the pre-training and the post-training, as well as the difference between pre-training and post-training. The relevant p-values are also included.

6.4.1 Awareness of Sexuality Policy

Earlier research has shown an awareness of an existing sexuality policy that can influence participants' perceptions regarding sexuality training (Tepper, 2000; Yool et al., 2003). Thus, data was analysed by two groups, namely a group that was aware of a policy (n=13) and a group that was unaware of a policy or unsure about the existence of a policy (n=18). The pre-training and post-training scores for these two groups were compared, as shown in Table 6.4.

Table 6.4: Influence of awareness of the sexuality policy on the difference between pre- and post-training knowledge (N=31)

Variable: Awareness of sexuality policy	Pre-training Mean	SD	Post-training Mean	SD	Difference between pre and post-test training mean	Wilcoxon test p-value
Not aware or unsure (n=18)	12.95	3.42	15.06	2.82	2.11	0.3815
Aware (n=13)	14.23	1.83	15.23	1.88	2.82	

* $p \leq 0.05$ indicating statistical significance on the 5% level of confidence

The p-value ($p = 0.3815$) indicates that the awareness of the sexuality policy did not have a statistically significant impact on the pre and post-training scores. However, the participants who were not aware of the policy or were unsure about the existence of a policy seemed to have learned more during training as their mean scores increased from 12.95 to 15.06, as shown in Table 6.4. The group that was aware of a policy only increased their mean scores from 14.23 to 15.23. The SD in the group that was aware of the policy is also smaller when compared to the “not aware” or “unsure” group, suggesting less variation in their responses (Steyn et al., 2000). Although more participants were not aware or unsure about the existence of the sexuality policy, the relatively high number who were aware ($n=13$) is important, given the fact that in some earlier studies, researchers reported that none of their participants were familiar with the policy regarding sexuality and relationships (Yool et al., 2003).

6.4.2 Church Attendance

Literature suggests that participation in religious activities, in particular church attendance, influences perceptions related to sexuality (Aunos & Feldman, 2002; Burling et al., 1994; Ryan & McConkey, 2000). Participants were grouped into three new groups based on the frequency of church attendance. Group 1 included those participants who attended church more often than once a week ($n=12$), Group 2 were those who attended church once a week ($n=11$), and Group 3 were those who attended church once a month ($n=8$). The pre-training and post-training scores for these three groups were compared using the Kruskal-Wallis Test, as shown in Table 6.5. The Kruskal-Wallis test can only be used if the different samples come from populations with the same general shape, but with possibly different medians (Steyn et al., 2000).

Table 6.5: Frequency of attending church-related activities on the difference between pre- and post-training knowledge (N=31)

Variable: Frequency of church attendance	Pre-training mean	SD	Post training mean	SD	Difference between pre and post-training mean	Kruskal Wallis Test p-value
More than once a week (n=12)	13.41	2.99	14.75	3.57	1.34	0.5899
Once a week (n=11)	14.09	2.77	15.45	1.51	1.36	
Once a month (n=8)	12.75	3.10	15.25	1.76	2.50	

* $p \leq 0.05$ indicating statistical significance on the 5% level of confidence

Table 6.5 shows when comparing the difference between the pre-training and post-training mean scores that there were no statistically significant differences among the three groups ($p = 0.5899$). This implies that the frequency with which participants attended church did not have a statistically significant impact on participants' change in scores from pre-training to post-training. This result was unexpected as previous research had shown that religion and attitude about sexuality are closely related, as religious beliefs inform moral judgement, which is used to decide if something is right or wrong (Lefkowitz et al., 2003). Earlier research demonstrated that caregivers who did not attend church were more in favour of people with intellectual disabilities to express their sexuality (Ryan & McConkey, 2000). However, based on the mean values, it would appear as if the group who attended once a month showed the biggest difference between their pre-training and post-training mean scores (2.50), implying that they had gained the most knowledge during training. The difference between the pre-training and post-training mean scores of the group who attended church once a week (1.36) and those who attended church more than once a week (1.34), was similar.

6.4.3 Work Experience at the Facility

Next, the influence of the length of time which participants had been working at the specific facility was investigated in order to determine its influence on their knowledge and attitudes as reflected by difference scores, as shown in Table 6.6. Research had shown that work experience has an effect on religion and attitudes about sexuality and that they are closely related, as religious beliefs inform moral judgment, which is used to decide if something is right or wrong (Lefkowitz et al., 2004). Earlier research demonstrated that caregivers who do not attend church were more in favour of people with intellectual disabilities to express their sexualities (Ryan & McConkey, 2000). In the Nottingham Study of Sexuality and Aging, Bouman et al.

(2007) reported that more work experience was generally predictive of more positive attitudes of care staff. Data was analysed by two groups, namely those who had worked at the specific adult residential care facility for less than nine years (n=20), and those who had worked there for nine years or more (n=11).

Table 6.6: Influence of work experience on the difference between pre- and post-training knowledge (N=31)

Variable: Length of time at facility	Pre-training mean	SD	Post training mean	SD	Difference between pre and post training mean	Wilcoxon Test p-value
Less than nine years (n=20)	13.40	3.3	14.85	2.89	1.45	0.5782
Nine years or more (n=11)	13.64	2.11	15.64	1.21	2.00	

*p≤0.05 indicating statistical significance on the 5% level of confidence

Table 6.6 shows that work experience at the specific residential care facility did not impact on the participants' change in pre- and post-training knowledge in a statistically significant way ($p = 0.5782$). Both groups had similar pre-training means, but the group who had been working for nine years or more at the facility had a slightly bigger difference between its pre-training and post-training mean scores (2.00) when compared to the group who had less than nine years of experience at the facility (1.45). This differs from the results of Karellou's (2003) research, which reported similar findings to a study Bouman et al. (2007) namely that having been employed for more years at a residential care facility resulted in more positive attitudes towards sexuality of individuals with intellectual disabilities.

6.4.4 Speaking About Sexuality to Women With Intellectual Disabilities

Literature states that if caregivers have more knowledge about a specific topic, for example, sexuality, they would probably talk to the women in their care about the topic (Plaute et al., 2002). Therefore, in instances where caregivers participating in training courses had previously spoken to the women with intellectual disabilities about sexuality education, the probability was higher that the participants had prior knowledge of the topic.

In order to determine whether speaking about sexuality to women with intellectual disabilities had an influence on the difference between their pre-training and post-training mean scores, participants were divided into two new groups, as shown in Table 6.7. The first group had never spoken to women about sexuality before (n=19), while the second group had done so (n=12).

Table 6.7: Influence of having spoken to women with intellectual disability about sexuality on the difference between pre- and post-training knowledge (N=31)

Variable: spoken about sexuality	Pre-training mean	SD	Post training mean	SD	Difference between pre and post training mean	Wilcoxon Test p-value
Never spoken to women about sexuality (n=19)	13.58	2.48	14.84	1.26	2.83	0.8862
Spoken to women about sexuality (n=12)	13.33	3.58	15.58	2.25	1.62	

* $p \leq 0.05$ indicating statistical significance on the 5% level of confidence

Table 6.7 shows that whether the participants had or had not spoken to women with intellectual disabilities about sexuality before did not impact on their pre and post-training knowledge in a statistically significant way ($p = 0.8862$). Both groups had similar pre-training means, namely 13.58 and 13.33 respectively. However, those who had never spoken to the women about sexuality before had a bigger difference between their pre and post-training mean score (2.83 versus 1.62), showing that they had gained more knowledge than the other group. The studies of both Christian et al. (2001) and Morales et al. (2011) stated that caregivers are more likely to discuss the topic of sexuality with individuals with intellectual disabilities if they believe that these individuals have the ability to consent to behaviour of a sexual nature.

6.4.5 Knowledge About Women With Intellectual Disabilities' Prior Exposure to Sexuality Training

In order to determine whether the participants' knowledge of whether the women in their care had previously been exposed to sexuality training, they were divided into three new groups. Group 1 stated that the women had not previously been exposed to sexuality education as far as they knew ($n=16$). Group 2 were unsure ($n=7$), while Group 3 stated that they knew the women had been exposed to sexuality education before ($n=8$). A Kruskal-Wallis test was performed to test for statistical significance between the pre-training and post-training mean scores of the three groups (Kerlinger & Lee, 2000).

Table 6.8: Knowledge of whether women with intellectual disabilities had previously been exposed to sexuality training on the difference between pre- and post-training knowledge (N=31)

Variable: knowledge of previous exposure	Pre-training mean	SD	Post training mean	SD	Difference between pre and post training mean	Kruskal-Wallis p-value
No (n=16)	14.13	2.55	15.13	3.07	1.00	0.137
Unsure (n=7)	14.00	1.83	15.97	1.72	1.57	
Yes (n=8)	11.75	3.81	14.75	1.49	3.00	

* $p \leq 0.05$ indicating statistical significance on the 5% level of confidence

Table 6.8 shows that the impact of the participants' knowledge of whether the women with intellectual disabilities had previously been exposed to sexuality training did not impact in a statistically significant manner on the difference between their pre and post-training mean scores ($p = 0.137$). However, the caregivers who said yes they were aware that women had previously been exposed showed the biggest increase (3.00) between their pre- and post-training mean scores.

6.4.6 Age

It has been documented in earlier research that age influences sexuality perceptions in that older individuals tend to be more conservative related to sexuality and relationship education than younger ones (Franco, Cardoso & Neto, 2012; Lafferty et al., 2012; Oliver, Anthony, Leimkuhl & Skillman, 2002). Lafferty et al. (2012) furthermore reported that younger caregivers were generally more positive compared to older caregivers regarding sexual awareness. Murray and Minnes in their 1994 study on staff attitudes towards sexuality of persons with intellectual disabilities found the same. In fact, in a study with three participant groups, namely parents of adults with intellectual disabilities, support staff who worked with these individuals with intellectual disabilities and a community sample, Cuskelly and Bryde (2007) reported that age was the most significant influence on attitudes towards the sexuality of individuals with moderate intellectual disability. In order to determine the impact of the age variable on participants' different mean scores, they were grouped into three groups according to their ages. Group 1 comprised 12 participants between the ages of 23 and 34 years, eight participants between the ages of 35 and 43 years, and 11 participants between the ages of 44 and 59 years.

Table 6.9: The influence of age on the difference between pre- and post-training knowledge (N=31)

Variable: Age	Pre-training mean	SD	Post- training mean	SD	Difference between pre- and post- training mean	Kruskal- Wallis Test p-value
23-34 years (n=12)	13.88	2.16	15.00	2.50	1.13	0.162
35-43 years (n=8)	11.91	3.47	14.58	3.14	2.67	
44-59 years (n=11)	14.90	1.81	15.81	1.25	0.90	

* $p \leq 0.05$ indicating statistical significance on the 5% level of confidence

From Table 6.9 it is clear that, unlike previous studies, age did not impact the difference between pre and post-training mean scores ($p = 0.162$) in a statistically significant way. The oldest group, 44 to 59 years of age, showed the smallest difference between their pre- and post-training mean score (0.90). They also had the highest post-training mean score (15.81) of the three groups, indicating that they had the most knowledge following the training.

6.5 TRAINING EVALUATION

Each participant was asked to comment on various aspects of the training in order to obtain a holistic view of the training. This was done by asking them to complete a training evaluation form at the end of the two-day training (Hepburn, Lewis, Tornatore, Sherman & Bremer, 2007). Statements regarding various aspects of the training were made, including the planning, training material, the training method, length of training, and participants' satisfaction with the training. Each of these aspects was determined by a combination of different questions included in the training evaluation questionnaire (see Appendix G). Table 6.10 presents the evaluation by participants related to the training. Participants had to state whether they agreed with the statement, disagreed or whether they were undecided. Results are shown in Table 6.10.

Table 6.10: Results from the training evaluation form completed by the participants after training (N=31)

Variable	Agree	%	Disagree	%	Un decided	%	Missing data	%
Planning								
Preparedness of the trainer	30	96.78	1	3.22	0	0	0	0
Logical planning	29	93.56	1	3.22	1	3.22	0	0
Training material								
Appropriateness and ease of activities	30	96.78	0	0	0	0	1	3.22
Ease of use of material	29	93.55	0	0	2	6.45	0	0
Relevance of teaching aids	29	93.55	0	0	2	6.45	0	0
Ease of social stories	30	96.78	0	0	1	3.22	0	0
Social stories are disability friendly	26	83.88	0	0	1	3.22	4	12.90
Training method								
Sufficient participation opportunities	30	96.78	0	0	0	0	1	3.22
Ease of understanding and following instructions	30	96.78	0	0	1	3.22	0	0
Understandability of terminology	26	83.87	0	0	5	16.13	0	0
Length of training								
Length of training	23	74.20	4	12.90	3	9.38	1	3.22
Satisfaction								
Usefulness of training	29	93.56	0	0	1	3.22	1	3.22
Helpfulness of training to explain sexuality	30	96.78	0	0	1	3.22	0	0
Comprehensiveness of training programme	28	90.33	0	0	2	6.45	1	3.22
Will recommend this training	30	96.78	0	0	1	3.22	0	0

*p<0.05 indicating statistical significance on the 5% level of confidence

From Table 6.10 it can be seen that participants overwhelmingly agreed that the training was helpful, although data were missing on some items, particularly the item pertaining to whether social stories were disability friendly. The aspect that most participants disagreed with or were undecided about was the statement that the length of training was sufficient. This aspect is explored in more depth in the section pertaining to recommendations for further training. The various aspects of the training that could have impacted on participants' perception and knowledge are now described in more detail.

6.5.1 Planning

Planning is a deliberate process that forms a vital component of training as it helps the trainer to be organised and stay on track, thus allowing him/her to train more and help participants reach the training objectives (Scrivener, 2011). The outcome of planning is thus a coherent framework that contains a logical sequence of activities, allowing the training to handle unexpected events (Stronge, 2007). Once planning is developed, effective trainers can continuously adapt it to fit the needs of the participants.

Most of the participants (93.56%) agreed that the researcher's training was logically planned and presented, although one of the participants was undecided and one disagreed. Except for one participant who disagreed, all the other participants (96.78%) agreed that the trainer was well prepared. In fact, when asked in the open-ended question for comment, Participant 19 stated in her own words: "*The trainer was very good at what she does and she was well prepared and I would really like her to teach us again*". In a sequential exploratory mixed method design the Qualitative phase informs the Quantitative phase, which impacts positively on the outcomes of the training. The planning for the training was preceded by focus groups (Chapter 3) and tested in the pilot study (Chapter 5), which impacted positively on the planning process (Creswell, 2013).

In this study, a systematic literature research was also conducted in order to identify appropriate training programmes that would meet the needs of adult women with intellectual disabilities who live in residential care facilities in South Africa. However, as none could be found that specifically addressed the name of the current study, three focus groups were held as the first step in the development of this custom-designed training programme. The effect of this planning process possibly impacted on how participants rated this aspect.

6.5.2 Training Material

Five questions, each with a different focus, formed the training material evaluation. Firstly, participants were asked to reflect on the appropriateness and ease of activities used. Save for one participant who did not complete this question, the remaining 30 participants (96.78%) stated that they agreed that the activities were appropriate and easy to use. In the training, careful consideration was given to the aspect, as adult learning principles show that activities which offer greater participation and involvement are seen as being more appropriate (Grunert, 1997). Active participation in learning ensures that participants engage with the

material, participate in the training and collaborate with each other (Topping & Stewart, 1998). Using appropriate material, small group discussions, role-play and debate encourages participants to actively engage in their learning. As such, they take more responsibility for their own learning, which in turn impacts motivation and performance (Grunert, 1997). Next, participants were asked about the ease of the material. Two participants (6.45%) were undecided about this statement while the rest agreed that the material was easy to use (93.55%). The material which was selected was aligned to the activity and the researcher ensured the use of appropriate props for the role-play activity that would appeal to adults, such as the magnet and plastic object, demonstrating attraction in the theme about appropriate and inappropriate touch (Theme 1). Material forms an important part of adult learning (Lafferty et al., 2012).

Related to this, participants were asked about the relevance of the teachings aids. The results were exactly the same as for the previous question, with 93.55% agreeing with this statement and 6.45% being undecided about this aspect. In the literature, the importance of including relevant teaching aids such as PowerPoint presentations which outline the most important aspects are often described (Garber, 2001; Tufte, 2005).

The fourth and fifth questions were related to social stories. Social stories were included in this study as there is research evidence supporting the value of these in improving social functioning, which was one of the main aims of the aSeRT training (Delano & Snell, 2006). Social stories are also claimed to be a convenient, unobtrusive intervention that could be included easily into various contexts with little effort required on the part of the trainer (Moyes, 2001; Scattone, Wilczynski, Edwards & Rabian, 2002).

When participants were asked about the ease of the social stories, all but one (96.78%) agreed that the social stories were easy to use. However, only 83.88% thought that the social stories were disability friendly. Four participants did not answer this question and one participant was undecided. Although social stories had primarily been developed with the purpose of teaching specific social skills to persons with intellectual disabilities, not all participants saw this link (Gray, 2000; 2003; 2010). As this was not an open-ended question, this aspect could unfortunately not be explored in more depth in order to determine why they had rated their answers in this manner.

6.5.3 Training Method

Participants agreed (96.78%) that the training method provided them with sufficient opportunities to participate in the various activities within each theme. Active participation in training is generally regarded as one of the cornerstones of adult learning (Rogers & Horrocks, 2010). Hence, ample opportunities for participation were created. Skills should be modelled, observed and practiced, reinforced and generalised and built on life experiences and knowledge of the participants, as adults need to connect new knowledge to their existing knowledge/experience base (Lieb, 2012). There are certain principles and skills inherent to the steps of teaching a specific skill, such as role-play, modelling, observation, group and individual practice, reinforcement and generalisation (Du Toit et al., 2003). Group activities were supported by role-play and group discussions, as adult learners are relevancy-orientated, implying that learning has to be applicable to their work responsibilities (Lieb, 2012). Group work is a dominant teaching technique as the aim of social skills and coping training is to teach skills, attitudes and knowledge needed in real life. Interaction with others is essential, and training should focus on helping them understand how the training will help them reach their goals (Kassins et al., 2011). The participants also felt that it was easy to understand and follow the instructions set out in the training (96.78%). In contrast to all of the high ratings obtained for the training methods, participants were in less agreement regarding the understandability of the terminology (83.87%). Although every possible attempt was made to keep the terminology as simple and easy as possible (for example, by adapting certain terms after the pilot study and including definitions of terms in the training manual that could cause possible confusion) this was still challenging. The fact that the participants in this training were mostly untrained caregivers who had limited training regarding sexuality possibly also contributed to the foreignness of the terminology. Furthermore, the fact that the whole training programme was conducted during a pilot study and adjustments made thereafter possibly contributed to high scores awarded to the training method.

6.5.4 Length of Training

One aspect that influences the accessibility of training is the length of time required, as it effectively takes participants away from their daily work (Rogers & Horrocks, 2010). A relatively short training period (two days) was thus selected. This was the aspect about which the participants were least positive. Only 74.20% of the participants agreed that the length of training was sufficient, while 12.90% felt that it was not sufficient, and 9.38% were undecided. When asked in open-ended format for comments, Participant 24 stated: *"I ask for the extension of training. The training was too short and the training was good"* (sic.)

Participant 28 was very specific in terms of what she thought about the length of the training: *“The training was very useful, especially for me as a caregiver. I’ve learned a lot I will be able to implement and put it into practice as well. According to my evaluation, two days is not enough. I need more training that will take at least one week”* (sic). One participant did not answer this question. Three hours were allocated to each of the four themes. Two hours focused on theoretical aspects and were aimed at enhancing understanding of the theory, while approximately one hour focused on the practical activities, for example, role-play. Follow-on requests or requests for an extension of the training are regarded as one of the satisfaction indicators of training (Rogers & Horrocks, 2010). This aspect will be further expanded on in Section 7.5 on recommendations for further training.

6.5.5 Satisfaction

This aspect was measured by looking at four separate satisfaction indicators, all dealing with specific aspects, as shown in Table 6.10. Firstly, participants were asked if they regarded the training as useful, to which 93.56% agreed. Secondly, they were asked if they regarded the training as being helpful to explain sexuality, to which 96.78% agreed, with one participant undecided. In the third instance, participants were asked if they found the training programme to be comprehensive. A total of 90.33% agreed, while 6.45% were undecided and one participant did not answer the question. In the fourth place, participants were asked if they would recommend this training to others. A recommendation of training generally implies that the training is endorsed by the participant and that he/she was satisfied by the training in general (Bora, 2014). In this study, except for one participant who was undecided, all other participants stated that they would recommend this training to others (96.78%).

Following the rating of individual aspects related to the training, participants were asked to provide an overall rating of their satisfaction with the training on a five-point Likert scale ranging from 1 = very poor, to 5 = very good. The overall rating of the training satisfaction is presented in Table 6.11.

Table 6.11: Overall rating of training satisfaction (N=31)

Ratings	Very poor	Poor	Average	Good	Very Good
Frequency	-	-	-	6 participants	22 participants
Percentage				19.35%	70.97%

* 3 participants did not complete this question, resulting in missing data

From Table 6.11 it is clear that all participants (except for the three who did not complete this question) rated the training as either “good” (19.35%) or “very good” (70.97%). When asked for comments in open-ended format, Participant 25 stated: *“I don’t have a bad comment. The training was good and I learn a lot that the people with intellectual disability they do need love and respect”* (sic). This results should, however, be interpreted with caution, as literature has shown that when participants enjoy training, they tend to afford a high rating (Kerlinger & Lee, 2000; Rogers & Horrocks, 2010).

In order to understand which of the training aspects participants most enjoyed, they were asked to list the three most enjoyable aspects of training in open-question format. As stated earlier, the link between enjoyment of training and participant satisfaction with training is well known (Van Heerden, 2008). Participants' open answers were encoded and similar answers grouped together in themes by two independent coders. After they had independently coded all the responses, they met and held discussions until a consensus was reached.

Even although participants were asked to list the three items that they most enjoyed, some participants listed only one aspect, for example, Participant 1 who stated that she enjoyed all the new information. In contrast, some participants named four aspects, for example, Participant 25 who mentioned social stories; the theme related to different types of relationships; the privacy and appropriate conversation theme, and the icebreakers. In total, 83 responses were generated. These were grouped into 16 themes and three overarching categories. Results pertaining to the training aspects that participants rated as most enjoyable are included in Table 6.12.

Table 6.12: Most enjoyable aspects of training (N=31)

Themes	Frequency	Comments
Training content (n=42)		
All aspects	n=1	This participant did not specify and simply stated that <i>"I enjoyed all the new information of the whole training"</i> .
General sexuality education	n=8	Responses were assigned to this theme if participants stated that they enjoyed <i>"the difference between sexuality and sex"</i> (Participant 26), or when they simply mentioned <i>"sexuality"</i> (Participant 31). Participant 10 stated that she enjoyed <i>"how she (the trainer) explained everything about sexuality"</i> .
Intellectual disability information	n=8	Although providing general information was not a separate focus, this information was embedded in the training, this information was found novel, relevant and important.
Myths about sexuality and intellectual disability	n=1	This participant specifically stated that she enjoyed learning about <i>"women with intellectual disability and misconceptions about sexuality"</i> (Participant 5). This aspect was discussed during the introduction of the training programme.
Rights of women with intellectual disability	n=1	Participant 16 stated they she enjoyed learning about <i>"the right of women with intellectual disability"</i> . This aspect was discussed during the reflections and final conclusions.
Theme 1: Appropriate and inappropriate touching	n=6	This theme was mentioned by name <i>"appropriate and inappropriate touch"</i> (Participants 2, 3, 13, 24, 27, 31).
Theme 2: Happy and unhappy secrets	n=2	Both of the two participants who mentioned this theme referred to the importance of understanding that private conversations can result in unhappy secrets.
Themes 3: Different types of relationships	n=13	Various participants listed this aspect. Some stating that they now understood the different types of relationships for the first time. They also understood their own relationship with the women in their care better (Theme 4).
Themes 4: Romantic relationships	n=2	Neither participant expanded on this aspect with one only simply listing <i>"romantic relationship"</i> and one stating <i>"Theme 4"</i> .
Training material (n=10)		
Training manual	n=1	One participant simply stated that she enjoyed the whole manual (Participant 10).
Social stories: not specified	n=4	Some participants stated that they enjoyed the social stories (Participants 18, 19, 26, 31), without specifying which story they specifically referred to.
Social story: all about hugs	n=5	Participants 4, 20, 21, 25 and 28 specifically specified that they enjoyed the "All about hugs" social story. Participant 28 qualified her answer by stating <i>"I never new that u can ask a person to give him/her a hug"</i> (sic).
Training method (n=31)		
General training method	n=4	<i>"I like the way she talks when she explains"</i> (Participant 10); <i>"we had lots of fun"</i> (Participant 19); <i>"the way she did represent the topic"</i> (Participant 30) and <i>"how she shared information"</i> (Participant 18) were the four comments made related to this theme.
Role-play: not specified	n=6	Participants 9, 12, 13, 22, 23 and 27 all listed <i>"role-play"</i> without providing further elaboration.
Role-play: happy and unhappy secrets	n=11	Eleven participants specifically stated that they enjoyed the role-play related to this theme. Participant 15 elaborated on her answer when she explained <i>"some are good to tell than to keep it because it is dangerous so you must not keep secrets"</i>

Themes	Frequency	Comments
Activities	n=7	Three participants simply mentioned " <i>activities</i> " without specifying which activities they referred to (Participants 10, 19, 29). Three participants specifically stated that they enjoyed the activities about different types of relationships (Participants 4, 13, 22). In fact, Participant 4 specifically mentioned the " <i>Relationship Sequencing Activity</i> ". Participant 5 stated that she specifically enjoyed the " <i>Activity Cards of Unhappy and Unhappy Secrets</i> ".
Icebreakers	n=3	Participants 23, 25 and 30 only listed " <i>icebreakers</i> " without providing further information on which of the icebreakers they specifically enjoyed.

From the above table it is clear that three broad categories of responses were mentioned, namely the content of the training, the training method and the training material. Furthermore, this analysis of participant responses also shows that one single theme should not take preference over the others as all four themes were mentioned by participants. However, it would appear that Theme 2 "Happy and Unhappy Secrets" was mentioned most frequently. It was unexpected that some of the aspects mentioned in the introduction (for example, myths about sexuality and intellectual disability) and in the closing (for example, the rights of women with intellectual disability) were rated as some of the aspects that were most enjoyable in the training. Even though participants were asked to list the three items that they most enjoyed, some participants listed only one aspect, while others mentioned more than the required three. Earlier studies showed that the theme "Romantic Relationships" is important in the lives of people with intellectual disabilities (Siebelink et al., 2006).

6.5.6 Recommendations for Further Training

An open-ended question regarding comments and suggestions for further training was included at the bottom of the training evaluation feedback form. Some 23 participants made one comment, five made two comments, two had no further suggestions but thanked the trainer for the good training, and one participant made no comment. As for the open-ended answers related to the most enjoyable aspects of the training, these comments were also encoded and analysed by theme by two independent coders using thematic analysis. After they had independently coded the responses they met and discussed their codes until a consensus was reached. Results are shown in Table 6.13.

Table 6.13: Suggestions and comments for further training (N=31)

Themes	Frequency	Comments
More training	n=3	These three did not specify exactly what they meant by stating “more training”. Therefore, it is unclear if they desired more training in terms of an increased length of training or more training in terms of more information.
More training in terms of content	n=7	These participants did not state exactly what type of content knowledge they were referring to for example, Participant 4 stated “ <i>I’d loved her to come again so that I can earn more information</i> ” (sic).
More information about disability	n=7	These seven participants were very clear that they required more information about disability aspects in general, for example, Participant 17 stated “ <i>I think she must come again for training us because it is important to us to help women with disabilities</i> ” (sic) or about intellectual disability specifically: “ <i>She must come again to train us more about intellectual disabilities and give the people about the information on how to deal with kinds of people</i> ” (sic) (Participant 9).
More information about sexuality	n=1	Participant 20 stated “ <i>Explain in deeper about sexuality and examples</i> ” (sic) indicating that this participant requires specific information about the topic.
More training on how to teach other people	n=10	These seven participants were all very clear in terms of requiring more information that would empower them to train other people, for example, other caregivers, parents and/or guardians and members of the community. For example, Participant 31 stated “ <i>Please prepare a special training for us for training more caregivers</i> ” (sic). Participant 22 reflected on what she thinks further training should entail by stating “ <i>I think that those parents or guardians living with those kinds of people should be advised and taught in order for them to bring them up</i> ” (sic). Participant 15 wrote the following comment: “ <i>Must come again so she can help us and we go to intellectual disabilities and to the communities</i> ” (sic).
Longer training	n=2	These two participants specified that they wanted a longer length of training but did not specify how much additional time they would need. Participant 29 wrote “ <i>I like more days. Two days is not enough to know everything</i> ” (sic).
Longer training: one week	n=3	These three participants also requested longer training but were specific in their suggestion that the training should be spread out over five days. For example, Participant 21 made the following comment “ <i>I recommend that the training should be given enough time like five days, not just two days</i> ” (sic).
No suggestions but commented that training was good	n=2	Both of these two participants enjoyed the training but did not make any suggestions, for example, “ <i>The training was very good, the timing and everything</i> ” (sic) (Participant 27).
No comment	n=1	One participant did not make any further comments.

The 36 comments made by the participants comprise of the 25 participants, who made one comment each, the one participant who did not comment, and the five participants who each made two comments. In Table

6.13 it is evident that the participants who had made suggestions for further training provided specific details regarding how they would see the training evolve. Fifteen of the participants stated that they wanted more training in terms of content, disability in general or sexuality. This would suggest that the participants found the training to be applicable and useful. Five participants requested a longer length of training with some specifying that at least a week of training was needed. Literature suggests increasing the length of training by exploring two different options, namely training in longer sessions but still delivered in one day as one alternative, or extending the training period to a week or even two weeks as a second alternative (Hepburn et al., 2007).

6.6 SUMMARY

This chapter started with a discussion of the reliability of the questions. It was explained that of the 36 content-specific questions, 21 questions proved to be reliable, using the Kuder-Richardson 20 formula for binary data. Next, the results demonstrated that caregivers who participated in the aSeRT training showed significant positive outcomes when their pre-training and post-training mean scores were compared. Six variables that could possibly influence knowledge and attitude change, namely awareness of the sexuality policy at the facility, church attendance, work experience, whether they had spoken about sexuality to the women with intellectual disability before, their knowledge about whether women with intellectual disability had been exposed to sexuality training before, and age were tested for statistical significance. Results showed that none of these variables impacted significantly on the difference between participants' pre and post-training knowledge gain. The chapter concluded by providing an evaluation of the training by discussing participants' perceptions of the planning of the training, the training material, the training method, the length of training and their satisfaction with the training. An analysis of the aspects which participants most enjoyed in the training was included. Finally, participants' recommendations for future training were discussed.

CHAPTER 7

Conclusions and Recommendations

7.1 INTRODUCTION

The main aim of this study was to describe the effect of a two-day, custom-designed sexuality and relationship training programme (the aSeRT) on the knowledge and attitudes of caregivers who work with women with intellectual disabilities at residential care facilities.

In Chapter 7, a summary of the results from the three phases of the study is presented. This is followed by a discussion of the clinical implications of the results. Next, a critical evaluation follows, highlighting both the strengths and the limitations of the study. Finally, recommendations for further research are provided.

7.2 SUMMARY OF RESULTS

The summary of the results is provided according to the three different phases.

7.2.1 Phase 1

Three different focus groups were conducted at a residential care facility for women with intellectual disabilities, as discussed in Chapter 3. All three focus groups had the same aim, namely to identify themes for the training programme using both the primary and secondary stakeholder groups. Focus Group 1 focused on 10 staff members of the residential care facility, while Focus Group 2 was conducted with the caregivers who took care of the women with intellectual disability at the facility. Lastly, Focus Group 3 was conducted with a group of ten women with intellectual disabilities themselves who met the specific participant selection criteria.

Staff at the residential care facility play an important role in the daily lives of women with intellectual disability and have a significant influence on how these women perceive their own sexuality and how they express themselves. A lack in basic knowledge related to sexuality matters was identified, specifically the knowledge in knowing the difference between sex and sexuality. The main themes identified were related to self-worth, (being liked and accepted); appropriate touch (displaying and receiving affection) and intimacy (showing thoughts and feelings). From Focus Group 2 it became evident that caregivers are the main educators of women with intellectual disability when it comes to socially appropriate behaviour and

role modelling. Therefore, they need knowledge and skill regarding sexuality education to facilitate the development of appropriate social skills. Despite the aim of the focus group in identifying possible themes for sexuality training, the results did not show themes but rather broader concepts that had to be addressed in a sexuality programme, as these caregivers' attitudes and perceptions often constrain the voices of the women with intellectual disability in their care. It became clear that caregivers needed to understand that these women are vulnerable and need information in order to protect themselves from sexual exploitation. In addition, the human rights of women with intellectual disability need to be clarified as well as the construct "intellectual disability". This should be done by keeping terminology as easy and straightforward as possible. Caregivers also expressed a need for resources to help them with various educational activities. Finally, they stated that a sexuality education training programme on relationship aspects such as friendships had substantial value for the women with intellectual disability. Following this focus group it became clear that caregivers should be the focus of this training if one hoped to achieve a change in the lives of women with intellectual disability. Focus Group 3 emphasised the importance and value of primary stakeholder involvement (women with intellectual disabilities themselves). They discussed aspects related to privacy and how they felt that they sometimes lacked privacy. During this focus group the women with intellectual disabilities' restricted educational opportunities which impacted on their literacy skills, as well as their limited means of communication, also became evident, as did their dependence on others, for example caregivers. This had significant implications for the method used during training.

In summary, the results from Phase 1 of this study indicated the themes that needed to be addressed in the training (appropriate and inappropriate touching, privacy and appropriate conversations, different types of relationships and romantic relationships). It also stressed that training caregivers would have the most noticeable outcome regarding increasing sexuality knowledge and fostering positive attitudes as a first step in addressing this complex matter. All three focus groups yielded information as to the method of training and appropriate training material, such as the importance of using role-play activities and stories with easy terminology and pictures.

7.2.2 Phase 2

Within Phase 2, the aSeRT was developed simultaneously with the measuring instrument as discussed in Chapters 4 and 5. First, a systematic search of literature was conducted to identify possible training methods and instruments. The training was developed based on an integration of the literature, which rests

on social systems theory specifically considering the policy system, the stakeholder system and the pedagogical system, as well as the information yielded from the focus groups. The measuring instrument was developed based on literature, after which an expert panel was approached to assist in reviewing the instrument. Both the training (comprising the training manual, a training pack with different items to be used during the different activities within each theme, and a social story booklet) and measuring instrument were field tested by means of three pilot studies.

Results from Pilot Study 1 indicated that the original Theme 2 (Public and Private Places) was inappropriate and had to be re-written to reflect privacy and appropriate conversations. Hence, a new Theme 2 (Privacy and Appropriate Conversations), which included the concept of “Happy and Unhappy Secrets”, was developed. Parts of Theme 4 which focused on dating were also changed and replaced with “Romantic Relationships”. Pilot Study 1 also indicated that changes were needed to Section B of the measuring instrument and hence, questions were refined and rephrased. Pilot Study 2 focused on the relevance and appropriateness of the newly written Theme 2. Results revealed that it was indeed suitable and only minor changes to the group activity “Dare to Share” were needed. The aim of Pilot Study 3 was to gauge the appropriateness of the adapted and refined measuring instrument. Results indicated that the content was appropriate, the instructions clear and the binary scale suitable. Hence, the measuring instrument could remain the same for the main study.

7.2.3 Phase 3

This phase constituted the application of the aSeRT and an evaluation of the training. Training material and equipment were provided to all 31 participants. The raw data were encoded by the researcher according to specific data definitions and data analysis and statistical procedures followed.

Overall, the results, as discussed in Chapter 6, suggest that the entirety of the two-day, custom-designed training programme (the aSeRT) had a significant effect on the knowledge and attitudes of the participants regarding sexuality education of women with intellectual impairments. Results also show that only 21 questions on the measuring instrument was regarded as reliable using the Kuder-Richardson 20 formula and therefore only these 21 questions were included in further analysis. In order to evaluate other variables that could possibly have influenced knowledge change (apart from the effect of the training), statistical analysis was performed. The effect of an awareness of a sexuality policy at the facility, church attendance, age, work experience, whether the caregivers had spoken to the women with intellectual disabilities about

sexuality before, as well as their knowledge of whether these women had been exposed to sexuality training before, were tested by means of the Wilcoxon and Kruskal-Wallis tests. All p-values were, however, larger than 0.05, indicating that none of these variables were statistically significant. Next, an analysis of the training evaluation was done. Results showed participants regarded the planning of the training, the training material and the training method as highly favourable. They were, however, not in agreement regarding the length of the training as many felt that the training should have been longer. Satisfaction ratings were also positive and corroborated the most enjoyable aspects of the training. Recommendations for further training mostly revolved around “more training”, which would suggest that the participants experienced the training as appropriate and beneficial.

7.3 CLINICAL IMPLICATIONS

The main clinical implication of this research is that a short training programme (two days) can be used successfully in the in-service sexuality education of caregivers at residential care facilities with the aim of explaining complex concepts in an easy, understandable manner in order to make it applicable to women with intellectual disability. The success of this training seems to be related to the following aspects:

- It is a custom-designed programme for caregivers at residential care facilities which was contextualised for women with an intellectual disability living in residential care facilities.
- It emphasises human rights and has the potential to empower women with intellectual disability and protect them from sexual exploitation. Following this training some of the caregivers stated that they had not been aware of these facts before. This illustrates that caregivers can be effectively equipped with knowledge regarding sexuality, which will also impact on their attitudes.
- The training utilises the stakeholder system as viewed from a social systems theory perspective in that it proposes that a secondary stakeholder group (caregivers) can be used to train the primary stakeholder group (women with intellectual disabilities) within a specific context.
- The combination of the activities used to exemplify each of the four themes and aimed at encouraging active participation, as well as the social stories which were written to illustrate a specific skill related to the theme, impacted positively on the caregivers’ understanding of the target concept.

7.4 EVALUATION OF THE STUDY

An evaluation of both the strengths and the limitations of the study are provided.

7.4.1 Strengths

- i) The sequential exploratory mixed method design that was implemented resulted in a custom-designed training programme which met the original aim of the research, namely to enhance the attitude and knowledge of caregivers at a residential care facility.
- ii) The aSeRT training programme consisted of different elements (a training manual, a training pack, and social story booklets), all of which fulfilled a specific role in the training and fostered adult learning.
- iii) A range of adult learning principles were incorporated during the training. These were considered to contribute to the positive outcomes of the current study and included an interactive, participation-based small-group training format which incorporated principles to promote active cooperative learning (Du Toit et al., 2003; Rogers & Horrocks, 2010). The use of a small group format was also considered valuable in providing an opportunity for participants to share and debate concepts among one another, to let go of misconceptions, and to consider other solutions for discussion with a group as a whole, which resulted in “cognitive restructuring” for the participants (Slavin, 1996, p. 50). Furthermore, the training sessions were generally found to be well-paced by participants. However, on Day 2 the participants seemed to become exhausted earlier during the sessions and the researcher had to take breaks earlier than on the previous day. This possibly points to fatigue in having to acquire a large body of new information. Finally, consistent use was made throughout the training session of repetition and revision of PowerPoint slides, in order to further integrate the participants’ thinking concerning the issues of barriers and the caregivers within residential care facilities, thereby internalising new learning concerning issues of personal significance to each participant (Slavin, 1996; Tufte, 2005).

7.4.2 Limitations

- i) Despite the advantages of the sequential exploratory mixed method design described earlier, this type of design is long and labour intensive, impacting on the time needed to complete a study of this nature, such as the current one.

- ii) Obtaining ethics approval and informed consent for the execution of this study was challenging. At first, the researcher tried to obtain consent from the parents or legal guardians of women with intellectual disabilities but this was problematic for various reasons. Some of the parents/guardians did not think that sexuality education was a relevant matter for their daughter with intellectual disability. Some of the parents/guardians lived far away from the residential care facility and could not afford to drive to the facility to attend an information session and/or to participate in training. Some parents/guardians refused without providing a reason and some parents were very old and had no interest in the importance of the topic at all. The relevant ethics committee at the University of Pretoria also asked numerous questions about the legal implication/s of the study, requesting proof of the women with intellectual disabilities' legal competency. The culmination of these aspects resulted in the decision to use a secondary stakeholder group (namely caregivers) as participants, as opposed to the primary stakeholder group (women with intellectual disabilities themselves).
- iii) Challenges were experienced in the recruitment of facilities to participate in this research. Many directors at these facilities stated that they regarded sexuality training as inappropriate or redundant. They expressed a fear that sexuality and relationship training would result in an increase in sexuality behaviour in women with intellectual disability – a behaviour they were actively trying to discourage and suppress. Some directors were in denial about any sexual activity in their facility and claimed that the women with intellectual disability were “asexual” and that the training would thus be redundant. These findings showcase the misconceptions and myths related to the sexuality of women with intellectual disability.
- iv) For the main study, the research was conducted at one specific residential care facility, limiting the generalisation of the findings. Furthermore, participants had to meet specific criteria and were asked upfront whether they were interested in attending the training focused on sexuality, which implied that they were already motivated when the training started, with a possibility of skewing the data to the positive side.
- v) Only 21 of the possible 36 content-related questions on the measuring instrument had appropriate reliability scores. Furthermore, these questions were not spread equally among the four themes

addressed in the training. This could have resulted in some gains achieved in the training not being captured, and hence an underrepresentation of attitude and knowledge change is possible.

- vi) A sleeping control group would have heightened the validity of the research results. However, due to the way in which caregivers interact with each other (in both informal and structured ways) and the limited number of caregivers at these facilities, results could have been contaminated had this been done.

7.5 RECOMMENDATIONS FOR FURTHER RESEARCH

Recommendations for further research stemming from this study are as follows:

- i) To duplicate this study with women with intellectual disabilities themselves as participants. This would show the direct impact of the aSeRT training with the primary stakeholder group and not with the secondary stakeholder group.
- ii) To develop an advocacy programme that could precede this training to heighten awareness of the importance of sexuality education for women with intellectual disability, and dispel common myths and misconceptions.
- iii) To compare the methodology that was used in the current study (namely active participation, icebreakers, creative repetition and reflection) with a different methodology (namely to provide the aSeRT training manual as a distance-based learning programme).
- iv) To extend the training to five days and to then compare the knowledge and attitude gain between the shorter (two day) and longer (five day) training in order to determine optimal length of training required by comparing different variables, such as gains made, manpower, loss of working hours, etcetera.
- v) To further refine and validate the measuring instrument.
- vi) To expand the training evaluation questionnaire to include more open-ended questions, as this could potentially enhance the quality of the feedback of specific elements. For example, a deeper understanding of how participants experienced the social stories and how they perceived their value could have been elicited in this manner.

7.6 SUMMARY

The current chapter provided the most important conclusions regarding the results of the study, as well as the clinical implications of the two-day aSeRT training. The strengths and limitations of the study were presented in an attempt to evaluate all the aspects of the study. Finally, recommendations were made as to how further studies would continue to add to the existing body of knowledge regarding this topic.

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APPENDIX A: ALPHABETICAL LITERATURE REVIEW RELATED TO SEXUALITY EDUCATION OF WOMEN WITH INTELLECTUAL DISABILITIES

Alphabetical Literature Review Related To Sexuality Education Of Women With Intellectual Disabilities

Author/s	Name/Article	Aim	Coding in terms of categories	Method	Significance	Limitations
Aunos, M., Feldman, M.A (2002).	Attitudes towards sexuality, sterilisation and parenting rights of persons with intellectual disabilities.	To review differences in attitudes of parents, service workers, teachers and persons with intellectual disabilities on sexuality.	-service workers -special education teachers -90 university students -Parents of children with intellectual disabilities -people with intellectual disabilities.	-literature review.	-three disapproved Service workers: variables that affect their attitudes are age, type of institution they work in, religion, frequency of interaction with clients, profession. Special education teachers: Few teachers have actually taught a course on sexuality because of lack of personal knowledge, fear of community reactions and lack of administrative support. University students: More than half had favorable attitudes Parents: -ambivalent or restrictive attitudes, avoiding talking about sex People with intellectual disabilities: -ten out of 13 acted as if sex was "a dirty and nasty business" of intercourse -eight had negative attitudes -persons with intellectual disabilities were less knowledgeable concerning sexual topics.	More updated studies needed comparing attitudes across types of respondents, determining what factors affect attitude and how attitude affects caregivers' support.

Author/s	Name/Article	Aim	Coding in terms of categories	Method	Significance	Limitations
Bazzo, G., Nota, L., Soresi, S., Ferrari, L., Minnes, P. (2007)	Attitudes of social service providers towards the sexuality of individuals with intellectual disability.	-to establish whether in Italy, social service providers' role and the service in which they work in could affect attitudes towards the sexual behaviour of individuals with intellectual disability, in particular direct-care tasks associated with a less liberal attitude.	-216 social service providers: -55 males -161 females -nine residential centers; -14 day centers; six outpatient treatment services.	-two page anonymous questionnaire handed to social service providers: 20 item sub-scale of a 40 item Sexuality and Mental Retardation Attitudes Inventory (SMRAI) (Brantlinger, 1983); -questionnaire items refer to sexual rights and sexuality stereo types of individuals with intellectual disability.	-significant differences in attitudes between those who operated in different services: staff in outpatient services revealed the most liberal and positive attitudes towards the sexuality of individuals with intellectual disability; closed institutions associated with less liberal attitudes.	-questionnaire gathered opinions on intellectual disability in general, while individuals with intellectual disabilities are a heterogeneous group, composed of people with different levels of difficulties and adjustment; -the sample size of social service providers was not significant for the study.
Bleazard, A.V. (2010)	Sexuality and intellectual disability: perspectives of young women with intellectual disability.	The contribution of intellectually disabled young women to the understanding of the sexuality needs and concerns of young women with intellectual disability.	Participants: *21 women who attended special school for nine years aged between 16-23 years; *Educators teaching senior or vocational phases at the school; *ten parents, guardians or foster parents of the young women with intellectual disabilities involved in the study.	Mixed method design: *Qualitative: interviewing *Quantitative: questionnaire.	Sexuality areas: Friendship Dating Sexuality education HIV/AIDS.	Difficulty generalising from 21 women participants to broader population of intellectually disabled women.
Bouman, W.P., Arcelus, J., & Benbow, S.M. (2007).	Nottingham Study of Sexuality and Aging. (NoSSA II). Attitudes of care staff regarding sexuality and residents: a study in residential and nursing homes.	-to determine the attitudes of care staff concerning sexuality toward later life in residential and nursing home facilities; -to determine the differences between the attitudes of care staff in residential and nursing homes regarding	-11 residential homes employing 258 permanent care staff and 8 nursing homes employing 237 permanent care staff.	-postal questionnaire; -the ASKAS, a psychometric test designed to assess an individual's knowledge and attitudes concerning sexuality among older adults: consists of a knowledge section and an attitudes	-significant negative association between age of care staff and the total scores; -managers in all care homes were more positive and permissive than nurses and care assistants: this finding would be in keeping with the existing literature, which	-level of education, having received staff education, ethnicity and own experience with sexuality not determined in the sample.

Author/s	Name/Article	Aim	Coding in terms of categories	Method	Significance	Limitations
		sexuality and residents.		section; -for the purpose of this study, only the attitudes section of the ASKAS was used.	reports that having received more vocational training, a higher educational level and having more work experience are generally predictive for more positive attitudes of care staff (Walker & Harrington, 2002).	
Brown, R.D., Pritle, T. (2008)	Beliefs of professional and family caregivers about the sexuality of individuals with intellectual disabilities: examining beliefs using a Q-methodological approach.	To describe the nature of the perceptions of involved adults concerning sexuality and sex education for individuals with intellectual disabilities.	Forty individuals who met the criteria of people who provide direct care or instruction to individuals with intellectual disabilities were selected through theoretical sampling.	Q-methodology approach; -concourse of 36 items was developed to reflect opinions of professionals who provide direct care or administrative responsibility of individuals with intellectual disabilities.	Each caregiver of individuals with disabilities approaches their caregiving predicated on their own belief system; this belief system of each professional will have some impact on the education and services provided to the individual with disabilities.	Cultural aspects of the belief system held by caregivers were not evaluated.
Christian, L., Stinson, J., Dotson, L. (2001)	Staff values regarding the sexual expression of women with developmental disabilities.	-to examine the attitudes and knowledge of support staff regarding issues of sexuality for the women they serve.	-participants included full and part-time support staff at an agency providing supported living, supported education, supported employment, and behaviour management day services to several hundred individuals with developmental disabilities.	-data were collected using a 41-item survey: it included both demographic and content items; -copies were randomly distributed to staff or left in their mailboxes; -75 surveys were distributed and 43 surveys were returned.	-most respondents agreed that women with developmental disabilities have the same sexual desires as women without disabilities (93%); -90.7% of staff agreed that women with disabilities should have the freedom and opportunity to express their sexuality; -81% of staff agreed that service providers were responsible for addressing the sexual wants and desires of the women they serve and in supporting their sexual expression;	-small sample size.

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					-most respondents agreed that women with developmental disabilities should be given the opportunity to receive sex education (93%) and more than half said they would be comfortable in implementing such training (61.(%).	
Coleman, E.M., Murphy, W.D. (1980)	A survey of sexual attitudes and sex education programmes among facilities for the mentally retarded.	-to gain a more accurate idea of the current status of sex education and attitudes toward sexuality in facilities for the mentally retarded.	-350 inpatient facilities were selected with a minimum of 50 patients.	-questionnaires were sent to all facilities via mail: 26 questionnaires were returned undelivered, five questionnaires returned unanswered,, one facility had been closed, two were facilities for the deaf, one considered the information confidential, one was too busy; -131 questionnaires were returned completed.	-the majority of the facilities approved of sexuality education, very few allowed for the expression of sexuality.	-it is not clear in the study who specifically in the facility responded to the questions.
Cuskelly, M., Bryde, R. (2004)	Attitudes towards the sexuality of adults with an intellectual disability: parents, support staff and a community sample.	-to examine the attitudes about the sexual expression of individuals with an intellectual disability held by parents of an adult with an intellectual disability, by support staff who worked in services for adults with an intellectual disability, and by the general community.	Participants: three groups: -parents of an adults with an intellectual disability (n=43); -support staff who worked with adults with an intellectual disability (n=62); -a community sample (n=63).	-an attitude scale was developed by pooling items from previously developed instruments that focused on attitudes to sexual expression of persons with intellectual disability.	-age was the most important influence on attitudes toward the sexuality of individuals with a moderate intellectual disability, with older respondents holding less liberal attitudes -parents were significantly older than staff in this sample, and these two groups did differ from each other in their attitudes.	-the study does not provide evidence that allows the comparison of attitudes towards the sexuality of persons with an intellectual disability and other groups; -the community sample is unlikely to be representative because of the way in which it was recruited; -the response rate of the parent and staff groups was not able to

Author/s	Name/Article	Aim	Coding in terms of categories	Method	Significance	Limitations
						be judged as the number of questionnaires distributed was not known; -those who chose to respond to the questionnaire were those who were more comfortable with the issue and who had more liberal views.
Cuskelly, M., Gilmore, L. (2007)	Attitudes to sexuality questionnaire (individuals with an intellectual disability): scale development and community norms.	-to establish the factor structure of the scale; -to undertake a separate examination of attitudes to the sexual expression of men and women with intellectual disabilities -comparing the attitudes to the sexual expression of individuals with an intellectual disability with attitudes to the sexual expression of typically developing adults.	-a sample of 261 adults (135 females) from the general community participated in the study; -their ages were grouped in 10 year aged brackets.	<i>Attitudes to Sexuality Questionnaire (Individuals with an Intellectual Disability: ASQ-ID)</i> -a second questionnaire was developed the <i>ASQ-GP for individuals from the general population</i> to measure attitudes toward sexual expression in adults without an intellectual disability.	The community recognised the multifaceted nature of sexual behaviour; The availability of a questionnaire that taps these multiple components will facilitate further research of these interrelated aspects of sexuality.	Respondents were known personally to their student interviewers may have biased their responses toward more positive or socially acceptable views; It is likely that participants who agreed to be interviewed on this sensitive topic felt more comfortable discussing sexuality and perhaps therefore held more accepting attitudes.
Esmail, S., Darry, K., Walter, A., & Knupp, H. (2010).	Attitudes and perceptions towards disability and sexuality.	To describe the current societal perceptions and attitudes surrounding sexuality and disability and to understand the basis of these views.	Participants criteria The study gathered data from four focus groups before and after participants view a short documentary film on sexuality and disability *each focus group had six-eight participants: service providers, individuals with visible physical disabilities, individuals with invisible disabilities, the general public.	Educational film: "SexAbility" -the film profiles the sexual lives of four individuals with varying disabilities illustrating how each individual experiences his/her own sexuality.	Direct quotes from participants: Such a relationship would "depend on the disability, if it is severe then maybe no"; Also an overlying "fear of being a caregiver rather than a partner". The public group also recognised the prevailing societal norm that encourages "people with disabilities to be with other people with disabilities". "my parents always said to	*Focus groups might not have elicited the most accurate information; *data collection could have been strengthened of one-to-one interviews had been completed prior to focus groups.

Author/s	Name/Article	Aim	Coding in terms of categories	Method	Significance	Limitations
					me 'you have to go out with someone that's disabled' – indicating that that some individuals with a disability are taught that their sexuality is not equivalent to those living without a disability.	
Evans, D.S., McGuire, B.E., Healey, E., Carley, S.N. (2009)	Sexuality and personal relationships for people with an intellectual disability. Part II: staff and family carer perspectives.	Assessing the attitudes of staff and family carers and exploring whether such attitudes are consistent with the ideological promotion of the sexual autonomy of those with an intellectual disability.	*staff carers (n=381) employed by a community based service for people with an intellectual disability; *family carers of those using the services (n=380.)	Questionnaire survey including case scenarios carried out with family (n= 155) and staff carers (n= 153) of people with an intellectual disability.	Utilisation of scenarios as a research methodology which has been shown to be effective in exploring issues of human sexuality; Staff carers more open to discussing sexuality and relationships and more likely to note environmental (insufficient training) as impediments to such discussion rather than service user characteristics (low cognitive ability).	Respondents primarily from a rural and small-sized urban region, therefore their views might not be representative of people from different settings; 40-41% response rate, therefore no information is available on those that did not participate, so the possibility of a sampling bias exists.
Gilmore, L., & Chambers, B (2010).	Intellectual disability and sexuality: attitudes of disability support staff and leisure industry employees.	To examine the attitudes in a sample of disability support staff focusing on the sexuality of individuals with intellectual disability compared to typically developing individuals and gender of the individual with an intellectual disability -attitudes of those who were working in a non-disability specific setting but who were likely to come into contact with persons with intellectual	Participants comprise two separate groups that differed in recruitment method, age, gender and distribution: -the first group consisted of 169 support staff (69% female) who were currently working with adults with an intellectual disability; -in the second group there were 50 employees (88%	-1 200 questionnaires were distributed to support staff within the organisation and 169 completed questionnaires were returned, accounting for 14% of those distributed.	-respondents generally demonstrated positive attitude towards the sexuality of individuals with intellectual disability.	-low return rare of questionnaires in the disability support group; -sample of leisure workers relatively small, no data given about their extent of prior contact with individuals with an intellectual disability; -general limitations of attitude research, particularly measuring attitudes related to disability and sensitive topics such as sexuality, include the tendency for respondents to report politically or socially correct responses and the fact that the

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		disability in those settings were examined in a sample of leisure and service industry employees.	female) from leisure and service industries who were likely to encounter adults with an intellectual disability during the course of their employment -disability support workers were recruited through a non-government organisation that offers accommodation, supported employment and activities for adults with intellectual disability.			extent to which these attitudes translate into actual behaviours is unknown.
Grieveo, 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.	The following hypotheses were investigated: -different staff groups will hold differing attitudes towards the sexuality of people with learning disabilities; -staff in residential facilities will pose differing attitudes towards the sexuality of people with learning disabilities in their care; -staff attitudes towards the sexuality of people with learning disabilities will be related to the level of the person's learning disability; -there will be a	Staff were selected from different types of residential facilities and had differing levels of professional qualifications.	An independent variable was employed, attitude towards the sexuality of people with learning disabilities, as measured on a standardised questionnaire; -main comparisons made were between different staff group, different residential settings and different categories of learning disabilities.	Care staff's conservatism shown to be most prevalent towards males who are homosexual and are living in nursing homes.	The study omitted questions regarding the type of experiences that people had in working with specific levels of learning disability.

Author/s	Name/Article	Aim	Coding in terms of categories	Method	Significance	Limitations
		relationship between staff age and staff attitudes towards the sexuality of people with learning disability.				
Healy, E., McGuire, B.E., Evans, D.S., Carley S.N. (2009)	Sexuality and personal relationships for people with an intellectual disability. Part 1: service user-perspectives.	-to determine the knowledge, experiences and attitudes of people with intellectual disabilities towards sexuality.	-potential participants were randomly selected from the service-user database in a community-based service for people with intellectual disability; -service users and parents/carers were contacted by letter; -service users placed in three separate categories based on age (i.e. 13-17 years; 18-30 years and 31+ years); -these groups were further divided into gender to encourage open discussion of possible sensitive material.	-focus groups.	Key themes: -different types of relationships -sex and related issues such as privacy, sex education, contraception, STD's, rules related to dating, sexual intercourse.	-lack of clarity and guidance at a policy and legal level related to sexuality issues.
Jorissen, S.L. (2008)	The attitudes of paid residential caregivers towards the sexuality of adults with developmental disabilities.	To determine how demographic factors correlate with those attitudes and how caregivers' predict that they would react in given situations in comparison to their measured attitudes would further	-Paid residential caregivers working with adults with developmental disabilities -experience in working in group homes; -all management staff required to have a	Part A: pilot study -to develop, validate and determine reliability of the DDSAS; Part B: main study -to examine correlations between demographic features of paid residential caregivers	-development of 2 survey instruments that proved to be useful in further research regarding attitudes that individuals hold about the sexuality and sexual behaviour of individuals with developmental disabilities; -possibility to implement a	Surveys conducted in face to face group situations so participants were able to ask questions if items were not understood, so the generalisability of the study is limited and the future results of those who would take the survey via e-mail or internet

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		benefit this process in order to determine if there is a predictive validity between the two and so these instruments can be used later to measure post intervention training effects.	bachelor's degree in a human services related field providing some kind of direct care contact.	and their attitudes about the sexuality of adults with developmental disabilities as assessed by the DDSAS.	social change by taking these instruments and using them as a basis for creating training materials regarding sexuality and adults with developmental disabilities; -create the potential to provide staff working in residential direct care and management staff with knowledge necessary to handle types of situations as they arise and provide residents with a positive quality of life change.	would be questionable without further analysis to determine reliability and validity.
Kamapalan, L., & Li, J. (2009)	Staff attitudes towards the sexuality of adults with intellectual disability in Singapore.	-examining the attitudes towards the sexuality of people with intellectual disability by service providers.	-staff from a voluntary welfare organisation who work with adults with an intellectual disability: three employment development centers.	-survey questionnaire completed by participants (ASQ-ID).	-caregivers are important to the social experiences and sexual identity of people with intellectual disabilities; -belief systems of caregivers must be examined before providing the needed sexuality education for adults with intellectual disabilities.	-lack of research in Singapore on attitudes of staff on sexuality; -research should focus on other settings as well; -increase sample size -organisations need sound policies regarding the expression of sexuality for people with intellectual disability.
Karellou, J. (2007)	Development of Parents' own child scale of the Greek sexuality attitudes questionnaire – learning disabilities (GSAQ-LD).	-to describe the development of a scale which assesses parents' attitudes towards the sexuality of their own child with learning disabilities; -to evaluate the new scale using data collected from a sample of 100 parents of people with learning	-a 100 parents living in Athens were asked either at group meetings or at individual interviews to participate.	-questionnaires and individual interviews.	--parents scored high on viewing their children on being capable of having romantic feelings for another person suggesting greater tolerance for individual choice regarding sexual behaviour and encourages access to sexual information and contraception.	-only two researchers provided information about the evaluation of their instruments and the information is limited; -they provided information that their measure had good reliability and external validity but they did not provide any proof to support the claim; -most of the researchers failed to examine perceptions of the

Author/s	Name/Article	Aim	Coding in terms of categories	Method	Significance	Limitations
		disabilities in Greece.				sexuality of normally developing people which could provide valuable information about similarities or differences in parental attitudes regarding the sexuality of people with or without learning disability.
Karellou, J. (2003)	Laypeople's attitudes towards the sexuality of people with learning disabilities in Greece.	To describe the development of an instrument which assesses attitudes towards the sexuality of people with and without learning disability in Greece?	-301 people; -convenience sample.	-questionnaires; -group group of people individually approached; -another group of people contacted at their place of work.	-test-retest correlation values were acceptingly high for all four scales.	-deletion of missing cases.
McConkey, R., Ryan, D. (2001)	Experiences of staff in dealing with client sexuality in services for teenagers and adults with intellectual disability.	To explore staff's experiences of service settings and providers and their attitudes to sexuality.	-17 centers for people with intellectual disabilities participated: statutory services, social services trust, two special schools and residential services.	-330 questionnaires were distributed: 150 completed questionnaires were returned.	-staff in residential settings rated themselves as more confident than day care staff in the area of sexuality.	-target population from a single geographical area.
Miodrag, N (2004)	An exploration of a socio-sexual education programmes for individuals with developmental disabilities: changes in knowledge and attitudes.	-to assess the impact of an intervention on changes in knowledge and attitudes.	-Ten participants were selected due to their developmental disability characteristics: five males and five females.	-Knowledge Questionnaire was used as a pre- and posttest evaluation.	Participation in the study provides an opportunity for people with developmental disabilities to learn about issues that are valued in society such as making informed choices, about sexual behaviour, social appropriateness and socio-emotional skills.	-small sample size.
Morales, G.E., Lopez, E.O. Mullet, E. (2011)	Acceptability of sexual relationships among people with learning disabilities: family and	To compare the attitudes towards sexual relationships among PLD of parents of children without disabilities with (a)	Participants criteria *270 adults composed of four groups: -120 parents of children without learning	*demographic questionnaire *participants scheduled individually/ small groups	Three clusters identified, first cluster termed <i>mainly acceptable</i> *effects of contraception and autonomy: (a) acceptability	*the hypothesis was not supported by the data.

Author/s	Name/Article	Aim	Coding in terms of categories	Method	Significance	Limitations
	professional caregivers' views in Mexico	the attitudes of family caregivers; (b) the attitudes of professional caregivers and; (c) other persons in charge.	disabilities; -75 family caregivers (parents of people with learning disabilities suffering from Down Syndrome and suffering from a neuro-motor disorder (50)) -75 professional caregivers.	*64 vignettes (Esterle, Sastre & Mullet, 2008).	higher when PLD was a male (b) when the PLD was relatively autonomous (c) when partners use contraceptive techniques; second cluster termed mainly unacceptable third cluster termed depending on circumstances.	
Murray, J.L., MacDonald, R.A.R., Brown, G., Levenson, V.L. (1999)	Staff attitudes towards the sexuality of individuals with learning disabilities: a service-related study of organisational policies.	-surveying staff attitudes towards client sexuality from three different agencies who provide services to individuals with intellectual disabilities in England. This study also focused on staff knowledge and use of formal organisational policies.	-332 employees from 3 organisations selected to participate 178 completed questionnaires were anonymously returned of those asked to participate (54%); -87 participants worked in a direct-care capacity: care assistants, support workers,, residential social workers; -15 participants workers in a healthcare capacity; -22 participants worked in a professional capacity; -34 participants worked in a managerial capacity.	-20 item subscales of the 40 item <i>Sexuality and Intellectual Disabilities Attitudes Inventory (SIDAI)</i> designed to measure to measure attitudes of staff employed by agencies providing services for clients with intellectual disabilities.	-178 participants reported moderate to highly liberal attitudes towards the sexuality of people with intellectual disabilities.	-the SIDAI focused on individuals with intellectual disabilities in general; -participants' responses might have depended on the functioning level, residential placement and socio-sexual behaviour of clients.
Murray, J.L., Minnes, P.M (1994)	Staff attitudes towards the sexuality of persons with intellectual	-to assess attitudes towards the sexuality of persons with intellectual disability held by staff	-300 employees working within client and community services that serves persons	-20 item subscale of the original 40 item <i>Sexuality and Mental Retardation Attitudes</i>	-younger staff members and those having a university education held most liberal attitudes towards the	-lack of support for the effects of contact variables on staff attitudes may reflect the absence of negative responses

Author/s	Name/Article	Aim	Coding in terms of categories	Method	Significance	Limitations
	disability.	employed in the field.	with intellectual disabilities: 248 females and 52 males.	<i>Inventory (SMRA)</i> developed by Brantlinger (1983) -161 completed questionnaires returned by subjects: 133 females, 28 males.	sexuality of persons with intellectual disability.	to questions regarding quality of contact with persons with intellectual disability.
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 normalization and community integration.	-to evaluate potential attitudinal discrepancies of community members regarding the acceptability of socio-sexual expression for persons with and without mental retardation; -to provide specific information regarding the attitudes of community members in early adulthood and late adulthood, and of direct-care residential paraprofessionals supporting adults with mental retardation.	-individuals in early adulthood (18-29 years): 148 undergraduate students -individuals in late adulthood (65 years and up): 42 adults from community activity centers -direct-care paraprofessionals supporting persons with mental retardation in residential community setting: 89 direct-care paraprofessional staff from two residential agencies supporting adults with mental retardation.	-18 item questionnaire using a 6-point Likert scale developed from the items from Konstantareas and Lunskey (1998) in their evaluation of attitudes toward sexual behaviours held by persons with mental retardation and autism were used.	-in general, individuals in the late adults group were significantly more conservative in acceptance of socio-sexual behaviours than the early adult and paraprofessional groups; -attitudinal discrepancies of paraprofessionals not found to differ from those in early adult group.	-questionnaire is relatively brief and does not survey attitudes regarding several controversial and important issues such as sterilisation and abortion; -almost all of the participants were Caucasian; -study only focuses on rural area.
Ousley, O.Y., Mesibov, G.B. (1991)	Sexual attitudes and knowledge of high-functioning adolescents and adults with autism.	To learn about the sexual attitudes, experiences, and knowledge of both male and female autistic adults.	41 subjects were interviewed: -21 high functioning autistic adults -20 mildly to moderately mentally retarded adults without autism.	Interview was divided into two sections: a sexuality vocabulary test and a multiple-choice questionnaire that assessed experiences and attitudes about sexuality and dating.	-males more interested in dating and sexuality than females in both groups and autistic subjects had less experience with sexuality than mentally retarded subjects without autism -significant correlation between sexuality knowledge and IQ.	-either caregivers or adults in residential care settings were included in the study.

Author/s	Name/Article	Aim	Coding in terms of categories	Method	Significance	Limitations
Plaute, W., Westling, D.L., & Cizek, B. (2002)	Sexuality education for adults with cognitive disabilities in Austria: surveys of attitudes and the development of a model programme.	To determine current status of knowledge and attitudes toward the sexuality of persons with cognitive disabilities and then describe the sexuality education programme that was implemented.	Participants: *Parents of individuals with disabilities *Professional educators *Residential staff *Gynecologists *Individuals with cognitive disabilities.	Expanded versions of Brantlinger's (1983) instrument Sexuality and the Mentally Retarded Attitude Inventory (SMRAI); *psychometric characteristics of this 40-item Likert –type scale, including reliability and validity were reported to be highly acceptable *the scale yields an overall score between 40 and 200, with a higher score indicating generally a more accepting or liberal attitude with regard to sexuality of persons with cognitive disabilities.	The implications of the surveys are threefold. First the results confirmed the need for sexuality education for persons with cognitive disabilities. Secondly, they suggest that it cannot be assumed that because professionals think the issue is that they will necessarily address it. Thirdly, because the results indicated a variation of attitudes among individuals related to personal age, education, religion and the location of residence. When presenting Special Love talks to professionals working directly with people with cognitive disabilities.	-short-term evaluation of attitudes.
Scotti, J.R., Slack, B.S., Bowman, R.A., Morris, T.L. (1996)	College student attitudes concerning sexuality of persons with mental retardation: development of the Perception of Sexuality Scale.	-to explore the attitudes that college students express concerning persons with mental retardation and their sexual behaviour – as compared to their own peer group – taking into account demographic and contact variables.	-135 undergraduate students enrolled in psychology courses; -the participants (62% female) ranged in age from 18-34 years; -equally distributed across freshman, sophomore, junior, and senior years in college.	<i>-Perceptions of Sexuality Scale (POS)</i> <i>-Global Perceptions Scale.</i>	-college students viewed various sexual behaviours of persons with mental retardation as being somewhat less acceptable.	-the expanded version of the POS was not used.
Siebelink, E.M., de Jong, M.D.T., Taal., E., Roelvink, L.	Sexuality and people with intellectual disabilities:	To investigate knowledge, attitudes, experience and needs in people with intellectual disabilities.	Selection of possible respondents based on 3 criteria: -Age of 18 years and	Structured interviews held with 76 people with intellectual disabilities; -interviews were	-results confirmed that romantic relationships and sexuality are important issues in the lives of people with	-lack the inclusion of direct caregivers as participants and no intervention.

Author/s	Name/Article	Aim	Coding in terms of categories	Method	Significance	Limitations
(2006)	assessment of knowledge, attitudes, experience and needs.		older; -participation would not be harmful to them (e.g. because of a known history of sexual abuse); and -sufficient cognitive skills, sight and hearing to take part in the interviews.	conducted by ten females employees of the service-providing agency who were trained to follow a strict interview protocol.	intellectual disabilities; -people with more sexual knowledge have more positive attitudes and people with more positive attitudes have more experiences and more needs.	
Swango-Wilson, A., (2009)	Perception of sex education for individuals with developmental and cognitive disability: a four cohort study	To discover the expectations for a sex education programme identified by individuals with DD/CD, parents of individuals with DD/CD, professionals who work with individuals with DD/CD and healthcare professionals who come into regular contact with individuals with DD/CD	-the DD/CD group consisted of individuals ranging from 23 years to 43 years of age living in an assisted living environment: one was married, one in a LT relationship, one exploring a sexual relationship; -parent sample (three females, children 18 years to 29 years); -developmental professional sample: health educator, a counselor, an administrator (work experience 5-30 years) -Healthcare professional sample: ten nurses, one physician (work experience 7-22 years).	-process of interviews	-parents identified the following themes: i) denial; ii) fear; -professionals identified themes: i) safety; ii) legal ramifications; -health professionals identified themes: i) general health issues; -DD/CD population identified a theme of relationship knowledge; ii) practical knowledge.	-ability to generalise data because of small sample size; -bias of interview; Sample was a convenience sample and not randomly chosen so ability to represent the views of the sample group is limited; Due to nature of vulnerable population included in the study, consent from guardians was obtained, in obtaining these consents the researcher was made aware of personal sexual abusive situations the individuals had experienced.
Swango-Wilson, A. (2008)	Caregiver perceptions and implications for sex	To explore the relationship between the caregivers' attitude of	-purposive convenience sample -survey administered to	-Perception of Sexuality Scale (POS) -demographic	-a significant relationship between attitude of sexual behaviour of the intellectual	-nature of relationship between attitude of sexual behaviour of the intellectually disabled

Author/s	Name/Article	Aim	Coding in terms of categories	Method	Significance	Limitations
	education for individuals with intellectual and developmental disabilities.	sexual behaviours and their perception that their agency will support a sex education programme -to explore the relationship between the caregiver's attitude of sexual behaviours and their perception that they can participate in a sex education programme? -to explore the relationship between the caregiver's attitude of their ability to participate in a sex education programme and their perception of agency support for a sex education programme?	160 participants: 85 completed.	questionnaire.	disability population and perceived ability of caregiver to participate in a sex education programme; -significant difference found between perception of caregiver's ability to participate in sex education and perception of agency support of sex education.	population and perceived ability of caregivers contradicts the theory of planned action.
Swango-Wilson, A. (2008)	Caregiver perception of sexual behaviours of individuals with intellectual disabilities.	To identify the perception held by caregivers regarding the sexual behaviours of individuals with intellectual disabilities.	Participants criteria -purposive convenience sample; -survey administered to 160 participants; -85 completed the sample.	-tools were utilized: i) the Perception of Sexuality Scale (POS) to measure perception of sexual behaviours; ii) demographic questionnaire.	-caregivers are necessary to the development of appropriate social skills for individuals with ID; -successful sexual programmes must first address attitudes and perceptions of primary caregivers; -caregivers are uncertain about appropriateness of sexual behaviours of individuals with ID; -significant relationship identified between age of caregiver and perception held regarding sexual behaviours;	Factors that influence caregiver perceptions of sexuality for the ID: the dynamics that influence perceptions held.

Author/s	Name/Article	Aim	Coding in terms of categories	Method	Significance	Limitations
					<p>The younger the caregiver, the more accepting the perception toward sexual behaviour of individuals with ID;</p> <p>-caregivers perception for themselves different from those for individuals with ID; behaviur that were identified that held significantly different perceptions were public display of affect, private display of affection, safe sex, and risky sex.</p>	
Szollos, A.A., McCabe, M.P. (1995)	The sexuality of people with mild intellectual disability: perceptions of clients and caregivers.	-to assess the sexuality of people with mild intellectual disability: results were compared with data collected from a sample of people without intellectual disability.	-25 subjects with mild intellectual disability -ten male; -five female; -ten care staff acted as comparison group; -39 volunteer students: -ten male; -29 female.	-Data collected through individual interviews -Sexual Knowledge Experience Feelings and Needs Scale: -Sex Ken-ID -Sex Ken-C.	-overall sexual knowledge and experience levels of people with mild intellectual disability are low; -both men and women showed deficits in knowledge; -this study provides preliminary support that people who are transferred from institutions to the community are taught little about matters directly related to sexuality.	-it cannot be generalised that all individuals with intellectual disabilities need birth control training or intervention; Each individual is unique, it is a population whose diversity probably supersedes that of any comparable population of normal individuals...each individual is unique and should be treated as such (McCabe, 1995).
Toomey, J.F. (1993)	Final report of the Bawnmore personal development programme: staff attitudes and sexuality programme development in Irish service organisation for people with	Sexuality education and the development of programme material, together with staff training and attitudes towards involvement in education and counseling, describing and evaluating programs.	-65 staff members who expressed interest in using the Bawnmore Personal Development Programme.	-survey to evaluate the effectiveness of the education programme, the effectiveness of staff training and attitudes towards involvement and the factors influencing continued involvement -77 item questionnaire	-new evaluation method employed that measures the level of success perceived by staff in their use of the programme; -significant relationship established between voluntary involvement and continuation.	-validity of the questionnaire was not tested.

Author/s	Name/Article	Aim	Coding in terms of categories	Method	Significance	Limitations
	mental handicap.			drafted and piloted.		
Trudel, G., Desjardins, G (1992)	Staff reactions toward the sexual behaviours of people living in institutional settings.	-to review studies concerning the staff's attitude toward the sexual behaviour of people living in institutions.	-five studies on staff's attitude toward sexuality of hospitalized patients with mental disorders; -14 studies on staff's attitude toward sexuality of institutionalised patients with intellectual disabilities.	-literature review.	-sexual policies and sexual education programmes for staff considered to be an important factor in the development of positive attitudes by the staff toward the sexual behaviours of residents.	-literature review limited to only a few studies.
Walker, B.L., Harrington, D. (2002)	Effects of staff training on staff knowledge and attitudes about sexuality.	three aims: -to help staff to identify the sexual and intimacy needs of residents of residents; -to recognise that those needs vary just as they do for younger people, and -to identify appropriate caregiver responses related to elderly sexuality.	-pilot test of each of the four modules of training material to test short-term effect.	-109 staff members from long term care facilities completed a pretest and a post-test.	-improvement found in three areas: i) need for sexuality and intimacy; ii) sexuality and dementia; iii) sexuality and aging.	-lack of control group; -two items did not significantly correlate with the total score.
Wilkenfeld B.F, Ballan, M.S (2011)	Educators' attitudes and beliefs towards the sexuality of individuals with developmental disabilities.	To examine the attitudes and beliefs of educators in a school programme and instructors in an Adults day service programme at an educational facility.	Participants criteria *five teachers in a school programme for children ages 3-21; *five instructors in an Adult Day Service Programme (mild to moderate intellectual disability) for men and woman over age 21; *all students have cognitive impairments and multiple physical disabilities; Participant	*In-depth interviews: 37 questions conducted by social worker; *interviews averaged 60 min in duration; *audio-taped.	a) sexuality as a basic human right; b) capacity to consent; c) the need for sexuality education.	*findings cannot be generalised due to small sample size; *study participants were non-Hispanic and White; *identified themes understudied in literature.

Author/s	Name/Article	Aim	Coding in terms of categories	Method	Significance	Limitations
			recruitment *verbal announcements at staff meetings and direct outreach via phone and e-mail.			
Yool, L., Langdon, P.E., Garner, K. (2003)	The attitudes of medium-secure unit staff toward the sexuality of adults with learning disabilities.	-to explore staff attitudes toward the sexuality of people with learning disabilities: to gain knowledge of the attitudes held by a cross-section of staff from different occupations; to highlight any training needs of staff with respect to the sexuality of adults with learning disabilities placed in a medium secure unit.	-four full-time staff members: consultant psychiatrist, senior care-worker, advocacy worker, domestic staff member.	-demographic questionnaire; -completed a 40-60 minute audio-recorded semi-structured interview; -debriefing session.	-staff held liberal attitudes with respect to sexuality, however less liberal attitudes with respect to decisions and the involvement of adults with learning disabilities in their own sexuality; -none of the staff were familiar with the local policy regarding the expression of sexuality and relationships.	-study included participants that were not aware of policies regarding sexuality and relationships.

APPENDIX B: DATA TRANSCRIPTS: FOCUS GROUP 1

Question 1

What important aspects do you think the social story movie highlight about relationships and women who have an intellectual disability?

Watter belangrike aspekte dink jy bring die sosiale storie na vore oor verhoudings en vrouens met intellektuele gestremdhede?

THEME: Friendship vs. relationship = sexual intimacy

The women with intellectual disability residing in the centre do not know the difference between having a friendship and having a romantic relationship. Being sexually active is high on their priority list.

RESPONSES

"...vriendskap..."

["...friendship..."]

"...die probleem hier by ons is die kinders kan nie vriendskap verstaan nie...as hulle 'n verhouding het nie..."

["...the problem here is that the children do not understand friendship when they do have a relationship..."]

"...Dan sê hulle "nee" ons is net vriende..."

["...then they say "no" we are just friends..."]

"...hulle is seksueel baie aktief en dit is hoekom hulle nie 'n vriendskap kan hê nie...as hulle 'n vriendskap het wil hulle seks ook hê..."

["...they very sexually active..." (pause) "...that's why they can't have like a friendship..." (pause) "...if they have friendship then they want to have sex..."]

"...vat A byvoorbeeld, hulle sien mekaar as vriende..."

["...take for example A, they see each other as friends" ...]

"...hulle gebruik die "rondawel" al vir jare nie meer nie..."

["...they have not been using the "rondawel" for years..."]

"...die een paartjie wat hier bly is in hierdie lang verhouding...dis soos 'n vriendskap, hulle is maar net daar vir mekaar, maar ek dink nie eers dat sy beseft hmmm... dat..." [Interruption by other participant...]

["...the one couple that stays here, having a long-term relationship...like a friendship, they just there for each other, but I don't think they even realize, hmmm....that][interruption by other participant..."]

"...amper soos broer en suster..." vriendskap

["...almost like brother and sister...friendship..."]

Question 2

What does the word "sexuality" mean to you?

Wat beteken die woord "seksualiteit" vir jou?

THEME: the misconception of sex vs sexuality

Sexuality encompasses fundamental aspects of who we are as women. It includes biological, psychological, social and cultural components.

RESPONSES

"...hoe jy oor jouself voel as 'n vrou..."

["...how you feel about yourself as a woman..."]

"...die manier wat jy behandel wil word as 'n vrou..."

["...the way you want to be treated as a woman..."]

"...seks...gelag en geggigel..."

["...sex...laughing and giggling..."]

'...iets wat jy aan seksualiteit kan koppel...die manier hoe ek na 'n sekere persoon sal kyk kan my dalk meer aangetrokke laat voel as die ander een..."

["...something you can link with sexuality..." (pause) the way I would look at a certain one might attract me more than the other one..."]

"...liefde..."

["...love..."]

"...daar moet gevoelens wees..."

["...there's got to be feelings..."]

"...moenie seks met ander mense bespreek nie..." (mompel en gelag)

["...do not discuss sex with other people..." (mumbling and laughing)]

Mede-fasiliteerder: "...as Liezel sou se ek kom na julle toe om oor seks te praat, wat sou julle gedoen het?..."

["...Co-facilitator asked "if Liezel said to you I am coming to talk to you about "sex", what would you have done?...""]

Participants responded with laughing and mumbling that they still would have attended out of curiosity.

Question 3

What do you think women with mild to moderate intellectual disabilities understand about their own sexuality?

Wat dink jy verstaan vrouens wat 'n intellektuele gestremdheid het oor seksualiteit?

THEME: boundaries vs context

The boundary in relation to the context is everything. The type of relationship these women are having determines their physical or distance maintained.

RESPONSES

"...hulle verstaan alles van seks..."

["...they understand everything about sex..."]

"...hulle hou daarvan om rondawel toe te gaan..."

["...they like going to the rondawel..."]

"...hulle doen nie wat 'n man en vrou veronderstel is om te doen nie..."

["...they don't do what a man and wife is supposed to do..."]

"...hulle is net saam...vir jare al..."

["...they just together...for years now..."]

"...en Y, vir haar gaan dit nou weer net oor seks..."

["...and Y, for her it is only about sex..."]

"...sy wag nie drie maande nie..."

["...she doesn't wait three months..."]

"...L sal enige een wat hier inkom druk, enige een..."

["...L will hug anybody that comes here, anybody..."]

"...ongeag of jy 'n personeellid is en of jy 'n vreemdeling is wat hier instap, hulle kom na jou toe, hulle wil jou druk, hulle wil met jou praat, hulle soek aandag..."

["...irrespective if it is a staffmember or a stranger that walks in here, they come to you, they want to hug you, they want to talk to you, they seek attention..."]

"...hulle hele wêreld gaan net daaroor om aandag te kry (pause) al sien hulle jou elke dag sal hulle jou honderd keer sê môre, môre, môre, môre, dis net om daai aandag by jou te kry..."

["...their whole world revolves around getting attention, although they see you everyday they will say "good morning" a hundred times, it is just to get that attention from you..."]

"...hy is haar vriend, sy ken sy familie so hy is haar vriend, hulle het geen konsep van uitgaan en hulle gaan in hierdie wereld in en soos daai ou nou, die ou is self nie lekker nie, ek meen nou gaan hy in 'n verhouding in en die meisie weet nie sy kan vir hom nê sê byvoorbeeld nie waar hy nou met haar nice is en sy geniet nou hierdie aandag so sy stel haar bloot vir hierdie ou hulle het geensins 'n idee van wat is rêrig reg nie alles gaan oor seks, ek meen hoeveel van hulle gaan huistoe wat hulle ge-abuse word by die huis waar die mense net plain seks het met hulle. Hulle het geen konsep van hulle mag nê sê nie..."

["...he is her friend, she knows his family, so he is her friend, they have no concept of dating and they go into this world like that guy, they guy himself is not well, I mean and know he goes into a relationship with a girl and the girl does not realize she can say "no" to him for example when he is nice to her and she enjoys the attention and in that way she exploits herself to him, they have no idea what is really right, everything is about sex, I mean how many of them go home that get abused at home where the people just have plain sex with them. They have no concept of that they are allowed to say "no" ..."]

[Co-facilitator asks:] *“Wat gebeur as hulle verhoudings nie uitwerk nie, wat is hulle gevoelens rondom dit?”*

[Co-facilitator: "...Wat happens if their relationships do not succeed, what are their feelings related to this?..."]

“...hulle kan nou met iemand baklei en dan 5 minute later het hulle iemand anders...”

[“...they can have a fight with someone and 5 minutes later they will have someone else...”]

“...wanneer hulle verhoudings nie uitwerk nie is daar ‘n alewige bakleiery tussen hulle... as dit nou ‘n meisie en ‘n meisie is, maar as dit tussen meisie en seun is, hulle ken nie die verskil tussen vriendskap en verhoudings nie...”

[“...When their relationships do not succeed there are always fights between them...if it is a girl and a girl, but if it is between a girl and a boy, they do not know the difference between friendship en relationships...”]

“...as hulle nou met iemand fight, more loop hulle weer saam met iemand anders...daar is nie emosies nie, hulle het nie waardes nie...”

[“...if they fight with someone, tomorrow they will be walking with someone else again...there is no emotions involved, they do not have any values...”]

“...S kan nee sê...”

[“...S can say “no”...”]

“...vat vir M, daai vriendinnetjie wat altyd vir haar kom kuier, dis haar girlfriend...”

[“...look at M, that friend of hers that always comes and visits her, that is her girlfriend...”]

“...maar dan kry jy vir A wat sal sê nee...”

[“...but then you get A that will say “no”...”]

“...R sal ook sê nee...” sy het die konsep van wat is...sy kan nee sê...”

[“...R will also say “no”...she gets the concept of what it is...she can say “no”...”]

“...ek praat nou van as iemand nou aan haar moet vat sal sy sê nee...”

[“...I am talking about if someone might touch her then she will say “no”...”]

“...kyk daar is ‘n ding waarmee ons hulle blok op dat hulle 3 maande moet wag voor hulle weer in ‘n verhouding mag ingaan juis om hulle te stop want hulle sal spring van vandag na môre na iemand anders toe...”

[“...look, there is something we stop them on that they have to wait three months before initiating another relationship for the mere reason that they will go from one relationship to the next...”]

“...veral as daar nuwe kinders in die sentrum inkom dan wil almal hulle relationship los en met die nuwe kind uitgaan...”

[“...especially if new children come into the centre, then everybody wants to break up and have a relationship with the new person...”]

Question 4

How will a training programme on sexuality education contribute to women with intellectual disabilities' lives?

Hoe sal 'n program oor seksualiteit bydrae tot die lewens van die vrouens met intellektueel gestremdhede?

THEME: Attitude of staff

The staff's attitude has a substantial influence on the behaviour related to sexuality as well as the attitude of the women with intellectual disabilities. Referring to the discussing below, the negative attitude will directly impact on the training programme.

NEGATIVE RESPONSES

"...ek dink hulle gaan vir dit luister..." maar (interruption by other participant)

["...I think they will listen to it...but..."] (interruption by other participant)

"...as hulle hier uitloop dan is dit verby..."

["...if they walk out of here then it is over..."]

"...dit sal nie wonderwerke verrig nie..."

["...it will not create miracles..."]

"...by die sentrum gaan dit nie 'n impak hê nie..."

["...at this centre it will not have an impact..."]

"...dit gaan nie 'n wonderwerk wees nie..."

["...it will not be a miracle..."]

"...dit kan positief wees maar ek kan nie sien nie dat dit enigsins in die sentrum 'n verskil gaan maak nie..."

["...it can be positive but I cannot see that it will in anyway make a difference in this centre..."]

"...dit sal miskien help vir 'n handjie vol mense, maar nie almal nie..." (residents)

["...it might help a few people, but not all of them..."] (residents)

"...dit gaan geen impak hê op haar lewe nie, E gaan E bly..."

["...it will not have any impact on her life, E will stay E..."]

"...maar nie soos wat almal dink dit gaan nie..."

["...not like everybody thinks it will..."]

POSITIVE RESPONSES

"...dit sal baie positief wees..."

["...it will be very positive..."]

"...dit kan werk..."

["...it can work..."]

"...vir die huisouers sal dit..."

[...for the caregivers it will..."]

"...hulle gaan Desembermaande huistoe of een keer op 'n naweek gaan hulle huistoe, dit gaan hulle bewus maak "yes"!"

["...they go home in December or once on a weekend they go home again, it will make them aware,"yes"!]

"...dan gaan daar een of twee wees waartoe dit sal deurdring..."

["...there will be one or two that will absorb the information..."]

"...en vir die huisouers self die inwoner kan beter hanteer en..." [interruption by other participant]

["...and for the caregivers themselves, they will be able to cope better with the residents and ..."] (interruption by other participant)

"...maar jy gaan 'n handjie vol bietjie kan help..."

["...but you are only going to help a small group..."]

"...dit sal 'n goeie ding wees...om te gee vir die huisouers...ek dink dit kan 'n verskil maak..."

["...it will be a good thing...to give to the caregivers...I think it can make a difference..."]

Question 5

What should/shouldn't be taught?

Watter inligting volgens julle is belangrik om in te sluit in die programme? Watter inligting moet uitgelaat word?

[Should be taught]

"...wat is die verskil tussen vriendskap, seks, verhoudings..."

["...what is the difference between friendship, sex, relationships..."]

"...verskillende tipes verhoudings..."

["...different types of relationships..."]

"...met familie, vreemdelinge..."

["...with family, strangers..."]

"...persoonlike grense..."

["...personal boundaries..."]

THEME: privacy

- Boundaries
- Body rights
- Personal space
- Permission

Shouldn't be taught

"...verkragting..." (moet glad nie die woord noem nie)

["...rape..."]

"...hulle het nou die ding gedoen, en hulle is nou kwaad vir daai een dan is hulle verkrag..."

["...they have done "it" now, and now they get angry with that person and then they tell everyone they have been raped..."]

"...dan wil hulle polisiesake hê en al sulke dinge..."

["...then they want to call the police plus all kinds of other things...."]

"...as jy dit vir hulle noem gaan hulle opkom met dit ook..."

["...if you have mentioned inappropriate touch they will come up with that too"]

"...sodra jy vir hulle 'n ding se molestering is verkeerd dan is almal gemolesteer..."

["...as soon as you mention that there is something such as sexual abuse and that it is wrong, then everybody claims to have been sexually abused..."]

THEME: Content of the programme

- Appropriate vocabulary

RESPONSES

Question 6

What type of issues have you had to deal with related to sexuality while working at the centre?

Watter ander aspekte wat aansluit by seksualiteit het julle al mee te doen gehad by die sentrum?

THEME: Sexual identity

Sexual identity, the behaviour results from the situation itself rather than a true choice

["...same sex relationships..."]

["...we have the males being friends and woman being friends with woman, but males and females can't be friends..."]

["...the males here they will have a relationship with a woman, but they are not very interested in a woman (pause) it is more to hide that they are attracted to a male..."]

Question 7

What issues would you find helpful to cover in a sexuality education programme?

Watter addisionele of ekstra inligting sal julle voordelig vind in die program oor seksualiteit?

THEME: Dating and romance

RESPONSES

Women with intellectual disabilities often express affection indiscriminately which can threaten socially acceptable behaviour and increase their vulnerability to sexual exploitation.

"...appropriate vs. inappropriate touch..."

["...promiscuity..."]

["...public vs. private places..."]

SUMMARY**Question 1****THEME: Friendship vs. relationship = sexual intimacy**

The three themes that emerged was friendship, relationships and intimacy. It was highlighted by the group that women with intellectual disabilities struggle to differentiate between different types of relationships and what is appropriate in various types of relationship categories.

The role that staff plays in the day to day living of women with intellectual disabilities can have a substantial influence on how they express their sexuality. There is a need to teach women with intellectual disabilities how to express themselves in an appropriate manner, acknowledge that the sexual expression of women with intellectual disabilities is still seen as a taboo. Often there is no opportunity for women with intellectual disabilities to form or maintain their sexuality. This suggests that if they are prevented from having age-appropriate sexuality experiences it might lead to sexually inappropriate behaviour, such as touching other inappropriately (Grieve, McClaren, Lindsay & Culling, 2008). Couwenhoven (2007) confirms that touch and affection errors occur because individuals with intellectual disabilities lack information or are unable to generalise information from one relationship, situation, or context to another.

Question 2**THEME: The misconception of sex vs sexuality**

The staff's inability to conceptualise the basic needs and meaning of "sexuality", that an individual's sexual development is based on a multi-dimensional process was evident. The basic needs include "being liked" and accepted (self-worth), displaying and receiving affection (appropriate touch), feeling valued (self-esteem – one's attitude towards oneself) and attractive (self-concept - features) and sharing thoughts and feelings (intimacy). Our understanding about what it means to be a male or female, to be sexual, to be attractive or to have a disability, influences how we act or respond in different environments (Couwenhoven, 2007).

Question 3**THEME: Boundaries vs context**

Varying needs for touch and affection are necessary and beneficial to all human beings. Most of us have learned over time to have these needs are met in socially accepted ways. Touch and affection could seem out of place as a result of the behaviour that does not match what society expects from adult women with intellectual disabilities. Women with intellectual disabilities are often "programmed" by their parents, caregivers and staff to express their affection inappropriately simply because of their disability. This increases women with intellectual disability's vulnerability to sexual abuse and exploitation. How do we assist them to express closeness and affection in socially acceptable ways without depriving them from touch?

Question 4**THEME: Attitude of staff**

Brantlinger (1983) argues that the rights of individuals with intellectual disabilities are governed invariably, not by the law, but by the feelings (attitude) and behaviours of the people who care for them. Furthermore,

Cuskelly and Bryde (2004) conducted a study examining parents, support staff and a community sample of university students' attitudes towards the sexuality of individuals with moderate learning disabilities. The results of the study showed that age was the most important variable, with older participants showing the most liberal attitudes (Cuskelly & Bryde, 2004).

Dominant voices within the focus group made it clear that they firmly believe that a training programme would make no difference to the women with intellectual disabilities' knowledge about their own sexuality. When exposed to negative attitudes, all persons, with or without disabilities, will learn that sexuality is a negative or unacceptable aspect of who he or she is. Couwenhoven (2007) confirms that individuals with disabilities are less likely to ask questions or engage their parents in conversations prompted by curiosity. This allows parents and caregivers to postpone teaching.

During the de-briefing session one of the focus-group members mentioned that the caregivers working at the Centre have an attitude problem.

Question 5

THEME: Privacy

- Body rights
- Public vs. private places
- Appropriate conversations
- Personal space: appropriate vs. inappropriate touch
- Permission
- Appropriate vocabulary

According to Couwenhoven (2007), sexuality involves most topics that involve and understanding of public vs. private concepts. Children with intellectual disabilities need more time to master toileting, bathing and dressing skills, requiring their parents or caregivers to be in their personal spaces for longer periods of time than typically developing children. In addition, children with intellectual disabilities take longer to develop and learn socialization skills which means that parents and caregivers watch, supervise and intervene a bit longer. The increased supervision and ongoing surveillance is often a part of life for our children who create an altered script that makes learning and understanding privacy concepts more difficult. This desensitises the child with an intellectual disability to the concept of "privacy" and its meaning and the confusion often leads to difficulties discriminating between public and private concepts.

Question 6

THEME : Sexual identity

Carers expressed ambiguity towards same sex sexual activities. According to Evans, McGuire, Healy and Carley (2009), staff and caregivers might misinterpret homosexuality as friendships or misdirect expressions of affection (Lofgren-Martenson, 2012). This directly undermines their human rights as service users to explore and develop their own sexual identity and preferences (Evans et al., 2004).

Question 7

THEME : Dating and romance

We usually keep some physical and emotional distance from acquaintances and strangers. Adults without disabilities inherently understand this concept and have the ability to adapt their levels of touch and affection based on the relationships they have with a specific person, adults with intellectual disabilities usually need considerable guidance with this social skill. Labelling relationships for individuals with intellectual disabilities and helping them *understand* different ways of greetings or types of affection within these relationships can contribute significantly in her life in becoming more socially appropriate.

APPENDIX C: DATA TRANSCRIPTS: FOCUS GROUP 2

Question 1

What important aspects do you think the social story movie highlight about relationships and women who have an intellectual disability?

Watter belangrike aspekte dink u bring die sosiale storie na vore oor verhoudings en vroue met intellektuele gestremdhede?

RESPONSES

THEME: Love is sex

Definition of a social story

Social stories emphasise social skills and explain and identify appropriate and inappropriate social interactions and behaviour. The use of social stories in sexuality education, specifically for women with intellectual disabilities appears to be a potentially advantageous intervention tool. Social stories include a descriptive sentence for example about the environment, a directive or appropriate response that help the individual understand expected behaviour, and a typical response by someone else to inappropriate behaviour.

Goal:

To share information that is easily understood, promoting an improved understanding of events and expectations, leading to more effective responses.

"...Down Sindroom is weer heeltemal anders, want hulle is die seksuele gedeelte is nie belangrik nie, dis vir hulle net die aanraking, Downsindroom is meer liefde, so hulle drukkies is genuine net drukkies, ek het nog nooit wat ek van bewus is 'n Downsindroom gesien wat ander gedagtes met iemand gehad het nie..."

["...Down Syndrome is totally different, the sexuality side for them is not important, for them it is just affection that matters, Down Syndrome is more about love, so their hugs are sincere, I am not aware from what I have seen that Down Syndrome people have other intentions..."]

"...J, maar hy doen dit want hy sien sy groter ouer maats doen dit, hulle leer hom..."

["...J, but he does it because he sees his other older friends does it and then they teach him..."]

Social story movie: 3 minutes

"...dit klink soos 'n ideale sentrum..."

["...that sounds like the ideal centre..."]

"...in die ander sentrum waar ek gewerk het, het ons meer Downs gehad (missing text) en hulle verhoudings was nooit seksueel gewees nie, okay hulle mag in elk geval nie, maar selfs in die sentrum, hoeveel van ons Downsindrome is seksueel aktief, nie een nie, omdat as hulle 'n meisie het gaan dit absoluut oor liefde daar is glad nie seks betrokke nie, hulle dink nie daaraan nie..."

["...in the other centre where I worked, we had more people with Downs and their relationships were not sexual, okay they were not allowed to in any case, but even in this centre how many of our Down Syndrome is sexually

active, not one, because if they have a girlfriend it is absolutely about love and sex is not involved, they do not think about it..."]

"...J, die enigste rede hoekom hy dit doen is omdat sy maats in die koshuis praat oor sulke dinge oor sulke bewegings en sulke goed, maar die meisies ook nie..."

["...J, the only reason why he does it is because his friends in the hostel talk about such things, about such movements and stuff, but not the girls either..."]

"...A wat weg is, sy was saam met K vir jare, maar K was te oud gewees, hy was ook 'n Downsindroom gewees, en dit is net genoeg gewees, ek weet nou nie in ander sentrums nie, die Downsindroom is meer net ek gaan uit, dit is absoluut alles, hoeveel van ons Downsindrome is seksueel aktief, nie een nie, omdat as hulle 'n meisie het gaan dit absoluut oor liefde daar is glad nie seks betrokke nie, hulle dink nie daaraan nie..."

["...A who left, she was with K for years, but K was too old, he also had Down Syndrome, and that was just enough, I do not know in other centres, for this Down Syndrome it was more than just dating, it was absolutely everything, how many of our Down Syndromes are sexually aktief?, not one, because if they do have a girlfriend it is absolutely all about love, there is no sex involved, they do not think about it..."]

[Researcher:] *Sal julle sê daar is 'n verskil tussen die verskillende gestremdhede?*

[Researcher: "...Would you say there is a difference between the different types of disabilities?..."]

"...ja, definitief, daar is, M ek dink nie sy is Downsindroom nie, ek dink dis 'n goeie bewys dat sy nie Downsindroom is nie omdat sy so seksueel bewus is van haarself. Ek het nog nooit Downsindroom gesien wat sê vanaand is die aand. Al hulle weet van die rondawel, so hulle sal sê ons soek die sleutel en dan gaan hulle soontoe maar hulle sit en kuier en hou handjies vas en drink koffie en daar is ander mense wat sê hulle sit en mors tyd nou daar, so hulle gaan soontoe maar, so nie een van hulle wat Downsindroom is het ooit (missing text) J het soontoe gegaan saam met X maar hy weet van wat die ouens hom vertel het en sê hy het dit en dit gedoen maar of hy dit ooit gedoen het glo ek nie, ons kan nou ongelukkig nie gaan kyk nie, somtyds wens ek, ek is 'n vlieg op die muur want die meerderheid van ons inwoners, dit gaan oor die daad, dit gaan nie oor liefde nie, dit gaan nie oor foreplay of iets nie, dit gaan oor..."

["...yes, definitely, there is M, I do not think she is Down Syndrome, I think it is proof that she is not Down Syndrome because she is so sexually aware of herself. I have never seen a Down Syndrome that has "said tonight is the night"! Although they know about the rondawel, they will say we need the key and then they will go there and hold hands and drink coffee, and there are people that say they only go there and waste time. J went there with X but he knows certain things from what the guys told him and said he did "this" and "that" but if he ever did, I do not believe he did, unfortunately we can not go and look, sometimes I wish I was a fly on the wall because the majority of residents actually do the actual physical act, there is no love, it is not about foreplay or something, it is about..."]

"...dit gaan oor klaarkry..."

["...just doing it and getting it over with..."]

"...die seuns hier gebruik die meisies se liggame om hulleself te bevredig want party van hulle gaan tien voor ses en ses uur is hulle terug..."

[“...the boys here just use the girls' bodies to satisfy themselves, because some of them go at ten to six and six o'clock they are back...”]

“...en die meisies gaan omdat dit is liefde, dis aandag dis...”

[“...and the girls go because that is love, that is attention...”]

“...hulle sien dit as liefde en dit is wat aanvaarbaar is, dit is wat mamma en pappa gedoen het, dit is wat normale mense doen, so ons doen dit omdat dit normaal is om te doen, maar hoeveel meisies bevrediging kry, twyfel ek verskriklik, want ek gaan baie pront uit praat, want D en J is 'n ander storie weer...”

[“...they see it as love and that is what is acceptable, that is what mommy and daddy does, that is what normal people do, so we do it because it is normal to do it, but how many girls actually get satisfied? I doubt that, because D and J is another story again...”]

“...D kom daar by my dan sê sy: “Ons moet gou maak Pa, ek soek die sleutel”, “Ok, hier is die sleutel”, dan gaan sy en J en dan 10 minute later is hulle terug, dan sê ek: “Jis J is julle klaar?” “Ja, Pa”, dan sê ek, “J het jy gekom?” “Nee ek weet nie!” Dan sê ek: “D en jy?” “Ja pa!” So of hulle nou weet of hulle 'n klimaks bereik het of nie, maar D sê sy het 'n klimaks bereik, J sê nee hy weet nie, dan weet ek ook nou nie want hoe verduidelik ek gewoonlik is dit anderste om maar die meerderheid van die meisies sal ek dink, hulle is nooit bevredig nie...”

[“...D comes to me and then she says “We must hurry, I want the key”, “Ok here is the key”, then she and J goes and 10 minutes later they are back, then I say “Gee” are you finished already?” “Yes, we are”, then I say, “J did you come?” “No, I don't know!” Then I say “D, and you?” “Yes!” So if they reached a climax or not, I don't know, so I think the majority of girls are never satisfied...”]

“...en toe het jy dit geniet? Dan sê sy ja...dan sê ek vir haar “Wat het jy gedoen?” Dan sê sy: “Nee Ma ons het daar gekom” en dan sê ek “En toe?” Sy sê: “En toe trek hy sy broek af” en ek sê “Toe?” “En toe klim hy bo-op my en toe maak hy klaar”. Daar is nie foreplay of soen mekaar of druk mekaar of...”

[“...so, dit you enjoy it? Then she says, “yes”...then I say to her “What did you do?”...Then she says, “We got there”, then I say “...and then?” Then she says :“And then he pulled his pants down ”...and then I said : “And then?”” “Then he climbed on top of me and finished off”. There is no foreplay or kissing or hugging each other...”]

[Researcher:] “...Vind daar enige tipe interaksie plaas op die perseel soos byvoorbeeld gesels hulle met mekaar?”

[Researcher: “...Is there any interaction that takes place on the property for example do the couples or males and females chat to one another?”]

“...ons het verskillende werkwinkels...”

[“...we have different workshops...”]

“...naweke ja, sal hulle bymekaar sit, sal hulle saam dorp toe gaan, sal hulle saam kerk toe gaan, hulle sal sit op die veld en musiek luister en so aan, met ander woorde hulle het net Woensdae, Donderdae, Vrydae, Saterdag en Sondag kuieraande. Van Maandag tot Vrydag is dit werkstye, so dis etenstye, so dis drie maaltye en teetyd wat hulle mekaar sien en kuier dan na-ure, kuieraande soos vanaand en gisteraand weer, hulle sit en kuier bymekaar en musiek luister en...”

["...weekends yes, they will sit together, they will go to town together, they will go to church together, they will sit in the field and listen to music, in other words, only Wednesdays, Thursdays, Fridays, Saturdays and Sundays is social evenings. From Monday to Friday there are work slots, so lunchtimes, three meals a day and tea times that they see each other en then social after hours. Social evenings they sit together and listen to music..."]

"...so hulle het ook maar net, ek dink soos normaal, ek sê altyd vir hulle: "Gaan na julle werksplekke toe, Ma en Pa gaan werk toe en hulle sien mekaar vanaand weer, so dis normaal om te gaan werk", maar van hulle, soos H weer, sy wil 24/7 by F wees, sy sal in die terapie huis sit sy sal wegslip en dan hardloop na sy werk toe en dan moet ons haar sleep skree-skree terug na haar plek toe en dan 'n rukkie later hardloop hy weer hier verby want sy is agter hom aan. Sy, in Afrikaans praat ons van "n wit lewe", sy het 'n 'wit lewe', sy kry net nie genoeg nie, sy is so erg, wanneer sy wel,...my vorige outjie wat hier was, S wat oorlede is, het sy so aangegaan een aand, as hulle klaar is daar moet ons nou, gaan kyk of die plek skoon is en so, en die een aand het ek toe nou daar gaan sluit en toe is die hele badkamer bemors met bloed en so aan. Ek stap toe op en gaan bel die huismoeder en ek sê vir haar: "J was nog hier gewees, kyk net of H ok is" en sy het gekyk en gesien daar is niks fout met H nie en toe dog ek laat ek gou na S gaan kyk, en sy denim wat hy aangehad het, dat sy alles geskeur het daarvoor, sy is so rof. Nou hierdie meisiekind is tot vandag toe nog so erg en haar boyfriend F is weg vir 2 weke en kort-kort loop sy met een van my outjies C, ek sê vir C, "Onthou net laas keer het C se ma-hulle die polisie gekry", toe roep ek vir M, toe sê ek vir M, sê jy, toe ons vir H ingevat het Teddiebeer Kliniek toe, sê bietjie vir C wat gebeur as jy met H slaap, toe sê M, "Ek het amper met my gat in die tronk beland", so, weet jy, jy moet hulle bang maak want C vergeet so vinning, sy geheue is so kort, dat hy vergeet baie vinnig, nou hopelik, hy het al klaar vergeet, ek is seker daarvan, want hy het klaar na die (missing text) geloop vanoggend, so 'n mens moet versigtig wees want K ken geen einde, geen perke, sy is hiperaktief, seksueel aktief..."

["...so they also just have, like normal...I always say to them, "Go to your workplaces, like mom and dad go to work en they see each other tonight again, so it is normal to go to work", but some of them like H, wants to be with F 24/7, she will sit in the therapy house and slip away and run to his work and then we have to drag her back to the therapy house, screaming. Later she will slip out again following him. She, in Afrikaans, we talk about a 'white life', she does not get enough, she is so bad that when there was a guy here at the centre previously, S, that has passed on, she carried on one night that we had to go and clean the rondawel, that one evening the whole bathroom was full of blood. I went to phone their hostel's caregiver to check on her if she was okay, which she was. J was still here with me. I thought let me just go and have a look at J. His denim pants were torn, she had torn everything in front, she was so rough. Now this girl uptill today is still so rough and when her boyfriend F is gone for two weeks then every now and then she walks around with one of the other guys, like C, and I just told C "Remember last time I called the police", and I called M and said to M he must tell C what happens when you sleep with H? What happened when we took H to the Teddy Bear Clinic? C's memory is so short. M said "I almost sat with my 'ass' in jail!" C has already forgotten because he walked to (missing text) this morning, so 'n person must be careful because K has no boundaries, she is hyperactive and sexually active..."]

Question 2

What does the word "sexuality" mean to you?

Wat beteken die woord "seksualiteit" vir jou?

THEME: Sex vs. sexuality

RESPONSES

[Researcher:] *"...Sal julle sê daar is 'n verskil tussen 'seks' en 'seksualiteit'?"*

[Researcher: "...Do you think there is a difference between 'sex' and 'sexuality'?"

"...ek glo nie hulle weet wat is die verskil tussen liefde en seks nie..."

["...I do not think they know what the difference is between love and sex..."]

[Researcher:] *"...as een van hulle na jou toe moet kom en jy moet dit vir hulle verduidelik wat sal jy sê?..."*

[Researcher: "...if one of them had to come to yo and you had to explain it to them, what would you say?..."]

"...om 'n vrou te wees..."

["...to be a woman..."]

[Researcher:] *"...sal julle sê seksualiteit sluit in om 'n vriendskap te hê, om uit te gaan met iemand, soos jy nou-nou gesê het, hulle wil 'n meisie hê, of die meisie wil 'n kêrel hê, om die verskil te weet tussen hoe moet jy optree in 'n publieke plek of 'n privaat plek, bv. 'n persoon wat besigheid kom doen by die sentrum? Dink julle meeste van die vroue weet hoe om op te tree voor 'n vreemdeling as dit kom by aanvaarbare aanraking?..."*

[Researcher: "...would you say sexuality includes having a friendship, to date someone, like you said just now, they want a girlfriend, or the girl wants a boyfriend, to know the difference how to behave in a public place or a private place, for example a person that does business with the centre? Do you think that most of the women know how to behave in the presence of a stranger if it comes to appropriate touch?..."]

"...jy weet dis moeilik, hulle gee nie om nie, partykeer doen hulle dinge aspris, hierdie meisies, as hulle weet daar kom 'n vrou wat hier sing sal hulle nou nie by die eetsaal wees omdat daar 'n gesingery is nie maar as sy weet Mev V kom en sy bring haar 10 tiener kleinkinder seuns, tienerseuns, is hulle daar, en dan hou hulle hulle dop..."

["...you know it is difficult, they do not care, sometimes they do things on purpose, these girls,, if they know there is a woman that is coming to perform and sing on stage they will not come near the event , but if they know Mrs V is being accompanied by her ten male grandchildren, they will be there, and stare..."]

"...hallo Pa, maak nie saak of die outjie 16 of 17 is nie, "...hallo Pa, dan sal hulle hang op hulle..."

[...hello Dad, it does not matter if the guy is 16 or 17 years old, "...hello Dad..then they will stick to them like glue..."]

"...dis aandag soek meer as enigiets..."

["...it is attention seeking more than anything else..."]

"...en dan sal party van die meisies aspris wees, hulle weet van dis 'n mooi persoon of 'n mooi ou so, "ek gaan my nou dom hou en ek gaan nou hang, ek gaan my gestrem hou en as ek met hulle praat daaroor dan raak hulle kwaad..."

["...and then some of the girls will be deliberate...they know that this is a beautiful person or a beautiful guy..."I am going to play stupid and act as if I am disabled and drag on him and when I reprimand them they get angry..."]

"...net die feit dat hulle aan iemand kan vat die healtyd..."

["...just the fact that they can touch someone all the time..."]

"...vernaam die meisies, die seuns ook, maar die meisies hulle weet nie wat is gepas en wat is nie gepas nie, hulle sal toe C hier ingetrek het, het G daar by sy venster (missing text) toe sê ek dit is nie reg nie, maar G is slinks, ongeag of dit nou (missing text) "Ag ek het nie geweet nie, Pa. Ek is jammer", maar ek weet vir 'n feit sy..."

["...especially the girls, the boys as well, but the girls do not know what is appropriate and what not, they will when C moved in here, G sat by the window, and I told her it is not right, but she is sly, but just says, "I did not know Dad. I am sorry", but I know for a fact she..."]

"...V hulle 'crave' aandag dan gooi sy a tantrum, "Pa, W haat haar, niemand hou van haar nie, sy gaan wegloop en haarself doodmaak"...

["...V craves attention then she throws a tantrum, "Dad, W hates her, nobody likes her, she is going to run away and kill herself..."]

Question 3

How could a training programme on sexuality education contribute to the lives of women?
Hoe kan 'n opvoedkundige program oor seksualiteit bydra tot vroue se lewens?

THEME: Communication of healthy boundaries

RESPONSES

"...vir die oomblik, ja..."

["...for a moment, yes..."]

"... 'n mens sal dit...gereelde..."

["...a person will have to...regularly..."]

"...elke liewe dag 'n repetisie van alles wat ons doen... dit sal 'n herhaling moet wees..."

["...every single day 'n repetition of everything will have to be done...and it will have to be a repetition..."]

[Researcher:] *"...was daar al oomblikke wat julle met die vrou moes praat oor seksualiteit...hou in gedagte was dit seks of seksualiteit?"*

[Researcher: "...were there moments that you have spoken to the women about sexuality...keep in mind, was it sex or sexuality?...?]

"...ek dink nie seksualiteit sowel as seks, dit moet 'n mens gereeld met hulle praat, want hulle sal gereeld na mens toe kom en sê: "Die een het my rondawel toe gevat en hy spring net op en hy spring af!", so hulle sal, die meisies sal met ons kom praat, M sal met L gaan dan sê sy: "Dit was so seer, ek gaan dit nooit weer doen nie", L gaan net aan dan is hy klaar dan staan hy op dan loop hy, sy kon eendag amper nie eers op die veld stap nie..."

["...I do not think sexuality as much sex, that you must talk to them about often, because they will come to you frequently and say: "This one took me to the rondawel and then he just jumps on and jumps off again!", so the girls will talk to us, M will go with L and then she says "It was so sore, I am never going to do it again", L will just continue and when he is done he will get up and leave, there was one day that she could not even walk outside..."]

"...hulle sal baie praat oor...hulle sal kom vertel dat hulle nie bevredig word nie of dat Y sal kom..."

["...they will talk about it often...they will come and tell that they are not being satisfied or that Y will come..."]

"...vertel sy in detail..."

["...she tells in detail..."]

"...sy het so te kere gegaan dat die matras van die bed af is..."

["...she carried on in such a way that the mattress fell off the bed..."]

[Researcher:] *"... hoe hanteer julle dit?..."*

["...Researcher:"...how do you handle this?..."

[Researcher:] *"...hoe voel jy daaroor C?..."* (skud sy kop, nee)

[Researcher: *"...how do you feel about it C?..."*] (just shakes his head, no)

"...C is nou omtrent so 'n jaar en 'n half hier, C sal hulle stuur..."

["...C has been at the centre for about one and a half years, C will send them...."]

"...gewoonlik sal die meisies kla hulle het net so op en af gesprong dan gaan ek na Pa W toe dan sê ek: "Weet jy wat jy moet vir daai seuns van jou sê, dit werk nie so nie, man..."

["...usually the girls will complain about the males behaviour, just jumping on and off, and then I go to Dad W and tell him : "Do you know what you should to tell those boys of yours, that is not the way it works, man..."]

"...dis net dit word nie so gedoen nie man, jy moet voel en jy moet weet, geniet dit, in die rondawel sy kry nie genoeg nie..."

["...that's just not the way it is done man, you must feel and you must know, enjoy it, in the rondawel, she does not get enough..."]

"...ja maar sy is gestraf tot die 14^{de} Oktober toe..."

["...yes, but she has been punished until the 14th of October..."]

"...hulle sal ook nogal met die susters praat..."

["...they also tend to talk to the nursing staff..."]

"...ek onthou toe M hier was. A het so 'n probleem met W gehad, en dan, W maar hy kry niks bevrediging nie, hy mag niks met A doen nie, hy moet sit in die hoekie en kyk of so iets van die aard of sy moet sit en kyk hoe hy homself help, toe moes ek en M praat met W toe sê ek: "Oka y, fine W", ons het met altwee gepraat, hulle het bietjie gesit gesoen en gevry, bietjie roompies gesmeer moet asseblief nie 'n kers kry nie, julle gaan die rondawel afbrand, bietjie roompies smeer, nou moet ek intiem raak want jy moet hulle vertel wat om te doen om hierdie meisie te bevredig"...ek dink dis baie moeilik, jy moet jou opinies en idees op hulle afdwing amper maar hulle weet rêrig nie..."

["...I remember when M was here. A had a problem with W, and then W, but he got no satisfaction, he was not allowed to do anything with A, he just had to sit in the corner and watch or she had to sit and watch how he satisfies himself sexually. Then M and me had to talk to W that they first had to kiss and rub some cream and get more intimate because you have to tell them how to satisfy the girl...I think it is very difficult, you have enforce your opinions and ideas on them almost, but they do not really know..."]

"...maar as W TV kyk en hy kyk pornografie, dan help hy homself en dit is fine, dit werk..."

["...but if W wants to watch TV and he watches pornography, then he masturbates and that is fine, it works..."]

"...dan is daar nie 'n probleem nie..."

["...then there is no problem..."]

"...maar as hy by 'n meisie kom, werk niks nie, niks wil opstaan nie, dis wat A so frustreer het, so dit was 'n moeilike storie, nou moet jy vir hom verduidelik jy kan nie net daar kom en op A spring nie, jy moet nommer 1 aangetrokke wees tot daai persoon, dan outomaties, gaan dinge reg wees, so op die ou einde is hulle uit hulle eie uit maar W het met geen meisie, selfs met B met wie hy uitgegaan het kan hy dit regkry nie, want sodra hy daar kom, is hy so lus die kwyl loop by sy mond uit, maar as hy daar kom kan niks gebeur nie en so ander mense het B gehelp om gelukkig te voel..."

["...but if it comes to a girl, nothing works, he cannot have an erection, that's what frustrated A so much, so it was difficult situation, now you must explain to him that "you can't just come and jump on A, you must, number one, be attracted to that person, then automatically, things will work out, so at the end of the day they went their separate ways, but W could not come right with any girl, even with B who he dated, as soon as he gets there nothing happens, so other people helped B to feel happy..."]

"...en soos ek sê hulle kan nie onderskei nie want daai keer, B het Maandag ingekom, Maandagmiddag toe ek op diens kom, toe kom een van my meisies daar, B het Maandag ingekom, toe kom een van my meisies daar en sê vir my, en sê vir my sy wil net vir my sê sy en B gaan nou uit, hoe werk dit? Hy was 20 jaar terug hierso gewees, dis nou my boyfriend. Ek sê vir haar wag nou, weet jy 'n verhouding werk nie so nie, soos ek sê, gisteraand moes ek eintlik gaan praat en soos ek sê, weet jy wat, julle sit nie buite die koshuis en kuier nie, en toe het hulle hier in die sitkamer, hier binnekant gesit..."

["...as I said, they cannot differentiate, because that particular time, B come in on the Monday, the Monday afternoon when I came on duty, one of the girls came there and told me that B is dating now, how does that work? He was here 20 years ago and now he is her boyfriend. I told her to wait, a relationship does not work like that, like I said, last night I should have spoken, "you know what you do not sit outside the hostel and social, then they came and sat in the lounge..."]

"...dis soos 'n ligskakelaar dit sit aan en af..."

["...it is like a light switch, it switches on and of..."]

"...hulle los en vat..."

["...they take and let go..."]

"...dit gaan vir party van hulle nie oor 'n verhouding nie, maar sodra iemand anderste ek moet iemand hê, dit gaan nie altyd oor seks nie, dit gaan oor ek moet net iemand hê, by my hê, sê: "Dis myne..."

["...for some of them it is not about a relationship, but as soon as someone else has someone they too have to have someone, it is not always about sex, it is about I have to have someone, with me, to be able to say "This is mine..."]

"...dan moet jy sien niemand mag met daai een praat of naby hulle kom waar hulle is nie want dan is hulle kwaad..."

["...then you must know that nobody is allowed to talk to that person or come near them where ever they are, otherwise they get angry..."]

"...soos A se verhoudings, haar verhoudings werk nooit uit nie, want sy is soos 'n kind, sy wil glad nie seks hê nie, sy sê "Dis 'n vieslike ding daai..." wat in haar verlede gebeur het, weet ek nie, sy sê: "Dis 'n vieslike ding, ek doen nie daai vieslike goed nie", maar tog gaan sy uit met outjies, sy het al die jare uitgegaan en nooit sulke dinge gedoen nie, besluit hy wil iemand anderste hê en hy gaan nou rondawel toe maar ook nie so baie nie, so vir hulle gaan dit net, vir die meisies baie keer, gaan dit oor "Ek moet iemand hê wat baie geld verdien, wat vir my kan sweets, chocolates en sigarette kan koop" met die hekwagte uitgaan wat meer as R70 'n week kry sodat hy my kan bederf anderste kry hy nie genoeg geld nie..."

["...like A's relationships, her relationships never succeeds, because she is like a child, she does not want to have sex, she says "It is a disgusting thing". What happened in her past, I do not know, she says: "it is a disgusting thing, I do not do disgusting things", although she does date guys, she has dated for years but has never done such things. Often, for the girls it is only about "I have to have someone who earns money that can buy them sweets, chocolates and cigarettes" such as the security at the gates that earn more than R 70 per week so that they can be spoilt, if not they do not earn enough money according to them..."]

"..hier is so 'n paar wat vaste verhoudings het vir lank, P en A, C en R..."

["...there is a few long-term relationships that have been together for a long time, P and A, C and R..."]

"...C en S is nou al 'n hele ruk wat hulle saam is..."

["...C and S have been together for quite some time now..."]

[Researcher:] *"..is daar vroue wat glad nie in verhoudings is nie?..."*

[Researcher: "...are there any woman that are not involved in relationships?..."]

"...weet jy wat M is glad nie in verhoudings nie, maar ons dink hulle kolf vir die ander span, ons dink hulle hou van hulle eie geslag..."

["...do you know what, M is not in relationships, but we think she might be batting for the other team, we think they like their own gender..."]

"...julle sal verbaas wees W, M het verlede week en Sondag soontoe gekom na die suster toe, toe sê sy sy weet nie wat gaan nou met haar aan nie, maar sy is nou baie lus vir 'n man, sy gaan nie met iemand uit nie..."

["...you will be surprised W, M came to the nurses station last week Sunday and said she does not know what is going on with her, but she has such a desire to have a man, but she is not dating anyone..."]

"...M het daai tyd gesê dat sy wel met J uitgegaan het, maar J kan nooit die plek kry om dit in te sit nie, maar tog het J ander mense verhoudings gehad en hulle is bevredig, soos S..."

["...M said that she was dating J, but that he could never find the place to put it in, although J did have relationships with other people and they were satisfied, like S..."]

"...en nog 'n ding is, daar is nie 'n ouderdomsverskil by hulle nie, hulle sien nie ouderdom raak nie, J is iets in die 30, D is in die 60, hulle sien nie ouderdom raak, V en A..."

["...and another thing, age difference does not matter to them, they do not see age, J is something in the 30's, D is in the 60's, they do not acknowledge age, V and A..."]

"...A is hoe oud? Laat 20's? V is in haar?..."

["...A is how old? Late 20's? V is in her?..."]

"...V is amper 60..."

["...V is almost 60..."]

"...Amper 60..."

["...Almost 60..."]

"...Vir hulle gaan dit oor (missing text) en toe ek begin het was daar nog 'n kleurgrens gewees, nou het eintlik daai kleurgrens gebreek, en M en B, P was 'n rassis gewees in my opinie, en hy het nou twee jaar terug met die polisie hier ingekom. B kom van 'n kinderhuis af, sy praat glad nie haar moedertaal nie, sy praat Afrikaans, dis haar taal, en klomp van die outjies wat van Zimbabwe af kom was agter haar aangewees, P het haar toe gekry, hy is so jaloers op hierdie meisiekind dat sy nie kan beweeg en dan skel hy haar uit, so nou die kleurgrens maak nie meer saak vir hulle nie, hulle sien nie kleur of ouderdom nie....."

["...for them it is about (missing text) and then when I started here, there was still a colour boundary, now the colour boundary has disappeared, and M and B, P was a racist in my opinion, and he came in here two years ago with the police. B comes from a children's home, she does not speak her mother tongue but speaks Afrikaans, that is her language, and a few of the guys that come from Zimbabwe liked her, P succeeded in having her as his girlfriend, he was so jealous, she couldn't move then he used to shout at her, so the colour boundary does not matter anymore, they do not see colour or age..."]

"...A..."

["...A..."]

"...RB met LR is 'n Indiër meisiekind, hy is verskriklik lief vir haar en dan B en B, B wil net swart wees..."

["...RB with LR is an Indian girl, he loves her very much and then B and B, B just wants to be black..."]

"...hy 'accuse' vir B..."

["...he accuses B..."]

"...maar B is 'n bietjie los dink ek, dis hoekom, maar as jy met haar praat dan sê sy: "Nee, Pa W, ek is nie so nie" maar ons weet mos..."

["...but B is a bit promiscuous, I think, that is why, but if you talk to her, then she says "No, Dad W, I am not like that" but we know that..."]

Question 6a

What information is important to include in a training programme about sexuality for women who have intellectual disabilities?

Watter tipe inligting dink u is belangrik om in te sluit in 'n opleidingsprogram oor seksualiteit vir vroue met 'n intellektuele gestremdheid?

THEME: Healthy relationships (longterm)

RESPONSES

"...hulle moet weet 'n verhouding is 'n langtermyn ding, dis iets wat hulle moet weet, vir hulle is dit, ons sê is bokspring hier rond, want hulle spring soos springhase rond, van verhouding tot verhouding, hulle moet weet wat liefde rêrig is, want 99,9% van hulle weet nie rêrig wat liefde is nie, hulle weet net van, ons moet in 'n verhouding wees, waarvoor weet hulle nie, hulle weet nie wat gaan aan nie, hulle moet weet wat liefde is, want hulle verstaan nie dit nie en hulle langtermyn, dis wat ons, dis ook hoekom ons daai beleid ingestel het dat wanneer jy uitmaak met jou boyfriend, jy gaan vir 3 maande nie uit met 'n ander ou nie, want gewoonlik het hulle gesprong van die een tot die ander een sommer die volgende dag en dan nog 'n 3 maande nadat hulle nou uitgegaan het om te kyk of daai verhouding nou werk, dan moet hulle nou nog 'n 3 maande wag voor hulle seksueel aktief kan wees..."

["...they must know a relationship should be long-term, that is something they should know, for them it is like a buck jumping around, because they jump from one relationship to the next, they must know what love really is, because 99.9% of them do not know what love really is, they only know that "we must be in a relationship", for what reason they do not know, they do not know what is going on, they must know what love is, because they do not understand it, it is long-term, the "policy" we gave them about when they break up, they are not allowed to date another guy for the next three months to see if that relationship will work, then they must wait another three months before they are sexually active..."]

"...dit is nie om hulle te straf nie, want kyk is iemand wat normaal is hopelik, as ek uitgaan en ek ontmoet iemand vanaand en ek gaan score : "Jammer man, maar ek moet wag vir 3 maande" gaan ek permanent eensaam wees dan, so ons probeer vir hulle nou leer dis nie normaal nie maar ons probeer vir hulle vastigheid leer..."

["...it is not to punish them, because for example if someone that is normal, hopefully, if I go out tonight and I meet someone and I am going to score, "Sorry man, but I have to wait three months" then I am going to be lonely permanently, so we are trying to teach them it is not normal but we are trying to teach them to be more secure..."]

"...C en R, R was nog nie eers veras nie toe staan die meisies tou, almal wil hom hê, toe sê ek: "Jinnee mense, weet julle wat, R gaan vir julle aan julle kele kom gryp, die arme vrou is nog nie eers veras nie", hy is 69, hierdie jong meisies is agter hom aan, dit kan nie liefde wees nie..."

["...C and R, R had not even been cremated yet and the girls were already lining up, everybody wanted him, you know what, so I said "Gee whizz people, R is going to come and grab you by your throats, the poor woman has not even been cremated yet", he is 69 years old, these young girls are chasing after him, it can't be love..."]

"...Wat is dit om 'n dame te wees?..."

["...What is it to be a lady?..."]

"...dit gaan nie net oor ouderdomsgroepe nie, iemand soos L sy is 'n 21- jarige meisiekind, maar haar verstand is die van 'n 3-jarige, sy sal met poppies speel en goed opsnay en skeur, hoe bereik jy haar? Sy sal alles wat jy vir haar gee vernietig, hoe bereik jy iemand wat eintlik in 'n 21- jarige liggaam is maar eintlik 'n 3-jarige is, hoe verduidelik jy vir haar? Sy weet wat sy geleer het by die huis en ongelukkig het sy nie geleer by die huis nie omdat daar molestering by die familie is en sulke goete so sy wil seks hê, sy sal daar gaan skree: "C ons gaan nou rondawel toe, ons gaan lekker kry vanaand." Kliphard..."

["...it is not just about age groups, somebody like L is a 21-year old girl, but her mind is that of a 3-year old, she will play with dolls and will cut up and tear stuff, how do you reach her? She will destroy everything you give her,

how do you reach someone that is in a 21-year old body with the mind of a 3-year old, how do you explain it to her? She knows what she was taught at home, but unfortunately sexual abuse took place by family so she wants sex, she will go screaming: "C we are going to the rondawel, we are going to have a good time tonight. Very loudly....."]

"...kliphard..."

[...very loudly..."]

"...en sy sal vieslike taal gebruik..."

[...and she will use fowl language..."]

"...maar omdat sy 'n 3-jarige is..."

[...but because she is a 3-year old..."]

"...sy gaan glad nie huistoe nie..."

[...she does not go home at all..."]

[Researcher:] *"...Wat dink julle van persoonlike spasie?..."*

[Researcher: "...What do you think about personal space..."]

"...jy kan dit elke dag vir hulle sê, jy kan byvoorbeeld vir hulle sê, my woonstel is my woonstel mense, respekteer my privaatheid, vir 'n halfuur sal hulle onthou en dan storm hulle maar weer daarin, 'n mens moet elke dag..."

[...you can tell them every day, for example, you can tell them, my flat is my flat people, respect my privacy, for a half an hour they will remember and then they will storm in there again, a person has to everyday..."]

[Researcher:] *"...dink julle praktiese voorbeelde gaan dalk beter wees?..."*

[Researcher: "...do you think practical examples will work better?..."]

"...beter wees ja..."

[...work better, yes..."]

[Example of social story: personal space]

"...die inwoners leer beter deur 'visualisation', jy sal sien hulle kyk TV en so aan, hulle leer soos H wat TV kyk, hy sing elke word wat John Cena sê, alles wat hy sien onthou hy..."

[...die residents learn better through visualisation, you will see they watch TV and so on, they teach H that watches TV, he sings every word that John Cena says, everything he sees he remembers..."]

"...as hulle kerk toe gaan, julle weet self, hulle sit in die kerk, hulle luister wat die dominee sê, hulle loop uit, hy trap op daai laaste trap, voor hulle bus toe gaan dan vloek hulle en skel hulle mekaar, dinge wat ek nie sal kan herhaal nie, so dit wat hulle gehoor het, het geen effek op hulle nie, ek sou graag wou hê hulle moet hulle opening, die dominees en pastore, kort en kragtig maak, maar nou gaan hulle aan en aan met stories en vra toe vir waarom het hulle vandag gepraat, "Oor die Here", Ja, dit weet ons..."

["...when they go to church, you know yourself, they sit in church, they listen what the minister says, they walk out, he steps on that last step, before they reach the bus they start swearing and arguing with each other, things I won't be able to repeat, so what they heard in church had no effect on them. I would prefer if the ministers and pastors keep the openings short and sweet, but now they carry on and on with stories. I asked the residents about what the minister spoke in church and they answered "About God", Yes, that we know..."]

Question 6b

What information is NOT important to include in a training programme about sexuality for women who have intellectual disabilities?

Watter tipe inligting dink u is NIE belangrik om in te sluit in 'n opleidingsprogram oor seksualiteit vir vroue met 'n intellektuele gestremdheid nie?

THEME: appropriate content/terminology for training programme

RESPONSES

"...verkragting..."

["...rape..."]

"...dit is wat gebeur het met N se storie, sy is nie verkrag nie, sy het in 'n badkamer ingegaan, sy het haar boyfriend gestuur om 'n radio te gaan haal en hy loop so stadig, teen daai tyd, intussen het sy haar klere uitgetrek en M het sy daad gedoen toe sê sy vir haar ma, "Ma, M het my gedoen" en, toe sê haar ma, "N jy is verkrag", sy het nie geweet wat verkrag beteken nie, toe roep ons haar in en toe praat ek en G met haar en 'n paar van ons, en ons vra: "Wat het gebeur?"; "M het my verkrag", toe sê ons "Wat is verkrag?", "Hy het my gedoen." So sy het nie geweet nie, maar haar mamma het vir haar gesê omdat hy 'n kleurling outjie is en sy is wit, dis verkragting, want sy keur nie goed, nie kleurgrens nie, so as 'n mens oor verkragting praat hier..."

["...this is what happened with N's story, she was not raped, she went into a bathroom, she sent her boyfriend to fetch the radio and he walks very slow and in that time, she had taken off her clothes and M did it with her and then she told her mom "Mom he did it with me" and then her mom said "N you were raped". N did not even know what rape meant. So I called her in and I spoke to her and G and we asked: "What happened?" and she said "M raped me" her and we asked her: "What is rape?" and she said "He did me", so she did not know, but her mommy told her, because he was coloured and she was white, it is rape, because she does not approve of multi-racial relationships, so if you talk about rape here..."]

"...S het gehou van C, groot lang verskriklike groot man, maar C het 'n meisie gehad daai tyd maar toe het sy in haar gedagtes nou 'n ding van omdat sy hom nie kan kry nie is sy verkrag en die huismoeder daai tyd, G het oorreegeer en dis polisie sake en die polisie kom hier uit, en ek sê vir S: "Luister hier, onthou net die Here sien wat gaan aan, as jy nou jok en vir die polisie lieg hieroor die storie, onthou die Here sien wat jy sê en eendag gaan jy moet antwoord doen..."

["...S liked C, tall huge, big man, but C had a girlfriend at that time but she had her thoughts on if she can't have him she had been raped and the caregiver at that time of their hostel overreacted and called the police and then I told S: "Listen here, remember that the Lord sees what is happening, if you lie now and lie to the police about this story, remember that the Lord sees what you are saying, and one day you will have to answer..."]

"...Okay Pa, ek het gejok, hy het nie op my..."

["...Okay Dad, I lied, he did not..."]

“...toe sê ek vir die polisie hulle is nie geloofwaardige mense, vandag sê hulle dit, more sê hulle hulle het nie, sodra daar stories oor verkragting kom, dan is almal skielik verkrag, môre sê elke tweede meisie, “Ek is verkrag”, maar dit is net miskien omdat die outjie nou nie, sy het geld gesoek vir sigarette, “..ek gaan Ma sê jy het my verkrag laas week...”

[“...so I told the police they are not people you can believe, today they say one thing and tomorrow they say they did not, as soon as their are stories going around about rape, tomorrow every second girl claims to have been raped, “I have been raped” but it might be only because the guy could not give her money for cigarettes “I am going to tell Mom you raped me last week...”]

“...alhoewel dit vir hulle belangrik is om te weet dat “inappropriate touching”...”

[“...although it is important for them to know about inappropriate touching...”]

“...respek...”

[“...respect...”]

“...die woord verkragting en dan loop hulle rond en almal is verkrag en dan kom hulle ook uit met ‘n twintigjarige storie, Ma, Pa, Oom of wie ook al het hulle verkrag...”

[“...the word “rape” and then they walk around and everybody has been raped and then they also come up with a twenty year old story, Mom, Dad, Uncle and whoever else raped them...”]

“...enige woord wat vir hulle vreemd of jy mag hulle nie mishandel nie, of jy mag hulle nie ‘abuse’ nie, dan hardloop almal dan gaan se hulle vir G... “Ek is geabuse” en “Ek is aangerand” en dan het almal dit oorgekom...”

[“...any word that is foreign or you are not allowed to physically abuse them, or you are not allowed to abuse them, they run to G and they tell him : “I have been abused” or “I have been assaulted” and then it happened to everybody...”]

“...soos M en S, M het hier in die perdehok gewillig gaan lê, S het om die baan geloop en sy het blykbaar haar pantie uitgetrek en hy het gesien jissie wat gaan hier aan...sy het hom so uitgelok en toe sy klaar is het...hulle gesien en sy het geweet S gaan vir my kom sê want hy was in my koshuis op daai stadium, toe hardloop sy gou-gou na die suster toe en sê sy is verkrag wat nie die geval was nie, toe kom die storie uit, nee maar sy het hom uitgelok so hulle het nie ‘n clue waaroor dit gaan nie..”

[“...like M and S, M went into the horse's stable willingly lying down, S walked around the track and she took off her panty and he see and was wondering what is going on here? She teased him and when she was finished she knew S was going to come and tell me because he was in my hostel at that time, she quickly ran to the nurses station and told the nurse that she was raped, which was not the case, then the story came out, no but she lured him out, so they have no clue what it is about...”]

“...ek wil nie sê dis onbelangrik nie, want verkragting is verskriklik en dit kan gebeur, ek dink net die woord ‘verkragting’ is...”

[“...I do not want to say it is not important, because rape is terrible, and it can happen, I just think the word “rape” is...”]

“...die inwoners is sulke klomp skinderbekkies, hulle loop so rond en kyk na mekaar en hou mekaar dop dat daar is min kere dat iets gebeur sonder dat iemand nie sien...”

["...the residents are such a bunch of little gossipers, they walk around and watch each other that there are very few times that something happens without somebody seeing it happen..."]

"...my wagte by die hek as hulle sien iemand loop in 'n hoek, hulle sal agter daai persoon aanloop so op 'n afstand soos die wat 'crossdress', hulle sal kyk in die ry tot D nou klaar 'ge-crossdress' het en rondgedans het en homself gehelp het en so aan en dan sal hulle my kom vertel, of hulle vat die selfoon en maak 'n movie van dit en dan wys hulle my en dan soos ek die hele tyd sê ek sien nooit hierdie dinge nie, B jy het nou die ander dag K gevang homself help om 'n hoek en draai, maar ek het nog nooit op so iets afgekome nie, maar die inwoners sal op dit afkom en dan "pak die een en die een het agter op die trappe in jou koshuis mekaar gehelp...so daar is altyd iemand, so die plek is groot, maar is te klein vir al die inwoners..."

["...my guards at the gate, if you see someone walk into a corner, they will follow that person at a distance like those who crossdress, they will watch until D is done crossdressing and dancing around and masturbated and then they will come and tell me, or they will use their cellphones and make a movie of it and then they will show me, so as I say I never see these things. B caught K the other day masturbating around the corner, but I have never come across something like that, but the residents will. The one got hold of the other one on the stairs the other day in the hostel...so there is always someone, so the place is big, but too small for all the residents..."]

"...so die kans dat dit gaan gebeur is skraal, daar is bewerings dat so iets gebeur het, maar as 'n mens dit ondersoek dan is dit gewoonlik nonsens, dan is dit 'n gewillige meisie wat eintlik 'gebrag' het oor dit en toe noem hulle dit maar verkragting..."

["...so chances that it is going to happen are minimal, but if there are rumours that something like that happened, but if a person investigates it, it is normally nonsense, then it is a girl who was willing that was actually bragging about what happened to her and then they just called it rape..."]

[Researcher:] "...Is daar enigiets wat julle nog onder my aandag wil bring wat julle dink belangrik is vir hierdie opleidingsprogram?..."

[Researcher: *"...Is there anything you want to bring under my attention that you think is important for this training programme?"*]

"...Weet jy wat, hierdie ding wat die meisies hulle onderklere vir die seuns ook gee. Dan sê die outjies: "Dra jou onderklere vir 'n week, moet dit nie 'change' nie, ek soek dit teen die einde van die week, ek soek jou onderklere", dan is daar daai gewillige meisies wat dit sal doen, en dit is vir my onaanvaarbaar..."

["...Do you know what? This thing about the girls giving their underwear to the boys. Then the guys say: "Wear your underwear for a week, don't change it, I want it by the end of the week, I want your underwear", then there are willing girls that will do it, and for me it is unacceptable..."]

"...dit gaan oor 'hygiene' maar dit gaan ook oor die outjies soek die vuil onderklere om oor sy kop te trek terwyl hy homself help, dis waaroor dit eintlik gaan, so hulle doen sulke onaanvaarbare goed, nou die meisie moet eintlik kan sê, "Weet jy wat, nee. Weet jy my onderklere is my privaatgoed, ek gaan dit was." Dit is iets wat ... 'boundaries'...absoluut..."

["...it is about hygiene, but it is also about the guys want the dirty underwear to pull over his head while he masturbates, that is what it is actually about, so they do such unacceptable things, the girl should actually be able to say "Do you know what, no. Do you now my underwear is my private stuff, I am going to wash it." It is something that ... boundaries... absolutely..."]

"...selfs as jy nou vat E en H, ek meen hulle begin skaars uitgaan dan koop hy vir haar bra's en panties en als, die minuut as hulle uitmaak dan wil hy die polisie bel as sy nie al sy panties en bra's terug gee nie, dan se hy vir my gaan hy die polisie bel as sy nie al sy goed teruggee nie..."

["...even if you take for instance E and H, I mean they barely started dating and he bought her bra's and panties and everything, the minute they break up, he wants to phone the police, if she does not return the panties and bra's, then he tells me he is going to phone the police if she does not return all the stuff..."]

"...nou wat gaan die polisie doen as hulle sê..."

["...now what will the police do if they say..."]

"...Sondag toe maak hulle op, laas week, jy kan maar vir haar sê, E sê vir hom hy moenie weer vir jou onderklere koop nie, as hy terugkom dan kom sy weer met 'n sak panties en bra's..."

["...Sunday they got back together again, last week, you can tell her, E said to him, that he must not buy her underwear again, when he comes back, she has a bag filled with panties and bra's again..."]

"...so dit is ook miskien in 'n verhouding, as jy iets wil gee vir iemand in 'n verhouding en jy maak uit, dit is gegee met liefde, moenie vir dit terug vra nie, dit gee ons nagmerries hier, want dan sal die meisies kom en sê: "Pa, ek soek al my DVD's en my CD's", dis darem nie te erg nie, maar die seuns wil al hulle panties en bra's wat hulle gegee het, of ek soek my onderbroek terug..."

["...maybe it is like that in a relationship, if you want to give someone something in a relationship and you break up, it was given with love, do not ask for it back, it gives us nightmares here, because the girls come and say: "Dad, I want all my DVD's and CD's back", that's not too bad, but the boys want all their panties and bra's that they gave the girls or underpants back..."]

"...as jy iets gee, op daai tydstip was jy lief vir daai person gewees so moenie nou vir dit terug gaan vra nie, weet jy dis erg daai, daai terug gee, opmaak, uitmaak, môre maak hulle uit, dan wil hulle alles terug hê, oormôre of 'n week later dan maak hulle weer bymekaar kom hulle uit, dan is dit weer alles terugdra na mekaar toe so ek laat dit nie toe dat hulle goed vir mekaar gee nie..."

["...if you give something to someone at that moment you loved that person, so do not ask for it back, it is bad, that giving back, making up, breaking up, tomorrow they break up again, then they want everything back again, the day after tomorrow or a week later they get together again, then it is giving it is giving each other stuff again so I do not allow them to give each other things anymore..."]

"...sy is dorp toe, sy het teruggekom, hy het weer vir haar panties en bra's gekoop..."

["...she went to town, she came back, he bought her panties and bra's again..."]

"...maar jy kan hom ook nie belet om dit te doen want dit is sy geld, sy meisie!..."

["...but you can't stop him from buying it because it is his money and his girlfriend..."]

"...soos jy sê, jy weet nie of die panties haar pas nie, maar ja..."

["...like you say, you do not know if the panties fit her, but yes..."]

Question 4

What do you think women understand about their own sexuality?

Wat dink u verstaan vroue oor hulle eie seksualiteit?

THEME: Friends vs. romance

RESPONSES

[Researcher:] *"...Sal seks en seksualiteit vir hulle dieselfde wees?..."*

[Researcher: *"...Will sex and sexuality be the same for them?..."*]

"...ja, vir hulle sal dit dieselfde wees..."

[*"...yes, it will be the same for them..."*]

"...aanvaarbaarheid, wat aanvaarbaar in 'n verhouding is en wat aanvaarbaar is as jy nie in 'n verhouding is nie, soos ek nou die ander dag baklei het met hulle oor die D, sy het 'n boyfriend, vir jare al, maar hy is uit, hy het uitgegaan met 'n voertuig, toe gaan sit C by haar, vir my is dit nie aanvaarbaar nie, want C is iemand wat 'n kans gaan vat, so jy het mos 'n 'boyfriend', staan op en loop en gaan sit in jou koshuis, jy hoef nie by 'n ander outjie, want hulle het ongelukkig...weet jy as ek by L gaan kuier en haar man is nie daar, ek ken myself en sy ken my, sy weet daar gaan niks gebeur nie, maar hulle nie, want as ek nou soos hulle optree, sodra L se man nou uit is en dan gaan ek my kans kry met haar, en dis wat hulle dan doen, so..."

[*"...acceptability, what is acceptable in a relationship and what is acceptable when you are not in a relationship, like I was fighting the other day with D about, she has a boyfriend, for years already, but he is out, he left with a vehicle, then C went and sat with her, for me it is not acceptable because C is someone that is going to take a chance, so you have a boyfriend, get up and walk away and go sit in your hostel, you do not have to be with another guy...it is like if I go and visit L and her husband is not there, I know myself and she knows me, nothing is going to happen, but they don't, because if I behave like them, as soon as L's husband is out then I am going to have my way with her, and that's what they do, so..."*]

"...ek meen C vat sy kans, 'try' hulle almal, druk en soen, en hulle weet nie van hulle moet vir hom sê, vriende..."

[*"...I mean C takes his chance, tries them all, hug and kiss, and they do not know they should tell him, friends..."*]

"...vriendskap..."

[*"...friendship..."*]

"...wat aanvaarbaar is tussen vriende en wat aanvaarbaar is as hulle in 'n verhouding is, dis hulle grootste probleem, hulle weet nie eintlik waaroor 'n verhouding gaan nie..."

[*"...what is acceptable between friends and what is acceptable when you are in a relationship, that is their biggest problem, they do not really know what a relationship is about..."*]

"...maar hulle kan jou sê as jy hulle vra wat is 'n verhouding, dan hulle sal vir jou 'explain', wat is die 'meaning' dan hoor jy wat dit is..."

[*"...but if you ask them what a relationship is they can tell you, then they will explain to you, what is the meaning and you will hear what it is..."*]

"...as jy hulle vra wat liefde is, hulle kan nie jou regtig antwoord nie..."

[*"...if you ask them what love is they can't really answer you..."*]

"...van hulle as jy hulle vra wat is liefde dan sê hulle vir jou seks..."

["...some of them if you ask them what love is they will tell you "sex" ..."]

"...sommige ouers hou hulle self blind..."

["...some parents act blind..."]

"...R speel met homself in die publiek..."

["...R plays with himself in public..."]

Question 5

What type of aspects not mentioned before about sexuality have you had to talk to the women about?
Oor watter ander aspekte nog nie voorheen genoem rakende seksualiteit moes u al voorheen met die vroue oor gesels?

THEME: inappropriate behaviour (boundaries)

RESPONSES

"...moet gereeld oor seks met inwoners praat, meisies is baie oop om oor dit te praat – hoe hulle nie bevredig word nie..."

["...must talk about sex frequently with the residents, the girls are very open to talk about it - how they are not satisfied..."]

"...L is so gefrustreerd want sy word nie bevredig nie..."

["...L is so frustrated because she is not satisfied..."]

"...hulle gaan maklik na die susters toe, ons vertel hulle meer oor wat om te doen – dra ons opinies en idees aan hulle oor – moet aangetrokke wees, roompies smeer, ens..."

["...it is easy for them to go to the nurses station, we tell them more about what to do - give them our opinions and ideas - they must be attracted, use body lotion, etc...."]

SUMMARY

Question 1

THEME: Love is sex

Caregivers are in the position to provide social skills needed to develop the awareness of sexuality and self-protection skills (Swango-Wilson, 2008). A mistaken belief often held by many caregivers is that individuals with intellectual disabilities are child-like and incapable of sexual feelings (Swango-Wilson, 2008). Caregivers have an important role to play when forming part of a woman with an intellectual disability's social experiences and sexual identity. Often caregivers will acknowledge the importance of the development of social skills within the social situations of women with intellectual disabilities, but report that these vulnerable populations are rarely left alone to explore their sexual identities. The inability that these women with intellectual disabilities have to explore their sexuality in healthy social settings sets limitations on opportunities of the development of friendships or healthy sexual relationships outside their immediate environment (Swango-Wilson, 2008). In addition, their ability to develop social decision-making skills to good and bad relationships is also limited.

Caregivers provide social experiences that allow women with intellectual disabilities to define their

personal space boundaries and the ability to recognise appropriate and inappropriate touching that violate their own personal boundaries. Swango-Wilson (2008) state that caregivers often acknowledge the importance of relationships and sexual roles of women with intellectual disabilities but skill development is not necessarily encouraged for these women to define these sexual roles. Caregivers are the main educators to women with intellectual disabilities to teach social skills through role modeling and social experiences. For training programmes to be successful on sexuality education, the attitudes and perceptions of caregivers need to be addressed first. Swango-Wilson (2008) confirms that studies indicate that the interpretation of caregivers' sexuality of the individual with an intellectual disability is different from the caregiver's behaviour itself.

According to Murray et al. (1999), the need to evaluate formal policies within institutions, which inform staff of specific procedures concerning client sexuality. Without effective sexuality education programmes, supported by appropriate policy and practice responses, the lives and experiences of women with intellectual disabilities will be further undervalued.

Implications: Participants could not relate social story movie to the first question. Different behaviours vs. different types of disabilities.

Question 2

THEME: Sex vs. sexuality

Implications: Continuous misconception of sex vs. sexuality was evident which made it difficult to elicit accurate responses to the specific questions.

Question 3

THEME: Communication of healthy boundaries

Implications: Caregivers within residential facilities providing direct care to women with intellectual disabilities should have policies and communication channels provided by management which will increase their sensitivity in responding to the sexuality related behaviours and needs of the women with whom they interact on a regular basis (Murray, MacDonald, Brown & Levenson, 1999).

The gap between the formal existing policy, the lack of an effective sexuality education programme and the actual practices related to the sexuality behaviour needs of the women with intellectual disability needs to be addressed.

Question 4

THEME: Friends vs. romance

Implications: Continuous misconception of sex vs. sexuality was evident which made it difficult to elicit accurate responses to the specific questions.

For training programmes to be successful on sexuality education, the attitudes and perceptions of caregivers need to be addressed first.

Question 5

THEME: Inappropriate behaviour (boundaries)

Implications: ["...same sex relationships..."]

Question 6a

THEME: Healthy relationships (longterm)

Implications: The difference between public places and private places.

The difference between appropriate and inappropriate touch.

A relationship is a longterm thing; What love really is; Sexuality vs. sex;

When you break up you have to wait for three months, try and make them wait;
Personal space – with business people – you have to tell them everyday – for example own privacy in your flat; How to behave like a lady; Wearing underwear for a week and then giving it to their boyfriends; Giving underwear as a present and after they break up, wanting it back.

The residents learn better through visualisation (TV). Everything they see they remember. You must keep it short and work with pictures.

Question 6b

Theme/s: Appropriate content/terminology for training programme

[Shouldn't be taught: "verkragting" en "molestering"]

APPENDIX D: DATA TRANSCRIPTS: FOCUS GROUP 3

Question 1

[What does the word 'sexuality' mean to you?]

Wat beteken die woord 'seksualiteit' vir jou?

THEME: Ingredients of a romantic relationship

RESPONSES

[Researcher:] *"...Wat is die verskil tussen "seks" en "seksualiteit"?"*

["...What is the difference between "sex" and "sexuality..."?]

[Researcher:] *"...Wat sal julle sê?..."*

[Researcher: "...What would you say?.."]

"Ek weet nie wat is die verskil nie"

[Researcher: "...I don't know what the difference is..."]

["...Sexuality is how you look on the outside but sex is what you do with someone else, like what we do when we go to the rondawel, it is more intimate, when you kissing and everything..."]

"...Maar sy praat Engels ek kan nie Engels verstaan nie..."

["...But she speaks English, I don't understand English..."]

[Researcher:] *"...T het nou gesê seks is meer soos die fisiese daad, wat jy in die rondawel doen, en seksualiteit is meer hoe jy lyk as vrou, seksualiteit gaan meer oor aanraking, hoe jy voel as vrou, jou selfbeeld, hoe jy voel wanneer jy saam met jou kêrel is..."*

[Researcher: "...T said sex is more like a physical thing, what you do in the rondawel, and sexuality is more how you look as a woman, sexuality is more about touching, how you feel as a woman, when you are with someone like your boyfriend..."]

[Researcher:] *"...So daar is definitief 'n verskil tussen 'seks' en 'seksualiteit' so dit gaan ook oor wanneer jy uitgaan met jou kêrel, as jy op 'n 'date' gaan, so as jy uitgaan vir koffie, of julle gaan fliiek, of julle gaan eet roomys, dit gaan ook daarvoor om te weet wanneer is jou verhouding gesond, 'n gesonde verhouding is wanneer jy weet hoe om op te tree in 'n publieke en 'n privaat plek..."*

[Researcher: "...So there is definitely a difference between "sex" and "sexuality", so it is also about when you go on a date with your boyfriend, if you go for coffee, or to the movies, or go for ice-cream, it is also about knowing when your relationship is healthy, a healthy relationship is when you know how to behave in a public place and a private place..."]

[Researcher:] *"...Hier is 'n prentjie van 'n badkamer en 'n prentjie van die Spur. Hier het ek opgeskryf 'Privaat' en 'Publiek'.*

[Researcher: "...Here is a picture of a bathroom and a picture of the Spur. Here I wrote "Private" and "Public..."]

[Researcher:] *"...Watter prentjie hoort by "Privaat?..."*

[Researcher: Which picture will go under "Private?..."]

[Researcher]: *"...Watter prentjie hoort by "Publiek?..."*

[Researcher: "...Which picture will go under "Public?..."

"...Die prentjie van die badkamer kom by "Privaat" en die prentjie van die Spur kom by "Publiek"..."

["...The picture of the bathroom goes under "Private" and the picture of the Spur under "Public"..."

[Researcher]: *"...Dan kry jy verskillende tipes verhoudings. Wat sou julle sê van wat se tipe verhoudings is hierdie prentjie? Dis 'n prentjie van 'n familie, ne? Waar sal julle hierdie prentjie plak? By familie..."*

[Researcher: "...Then you get different types of relationships. What would you say about what type of relationships is in this picture? It is a picture of a family? Yes! Where would you stick this picture? With "family"..."

[Researcher]: *"...Vrouens het verhoudings met vriende en vriendinne, hierdie prentjie is van 'n vrou met 'n klomp mans waarmee sy gemaklik gesels, waar sal julle hom plak? Vriende..."*

[Researcher: "women have relationships with boy friends and girl friends, this picture is a woman with a few men whom she can chat with easily, where would you stick this picture?....Friends..."

[Researcher]: *"...Sê nou maar julle gaan na 'n konsert toe van Juanita du Plessis en jy is in die gehoor, wie is die mense om jou? Vriende, vreemdelinge ?..."*

[Researcher: "...Say for example you are going to a concert of Juanita du Plessis and you are in the audience, who are the people around you?...Friends, strangers ?..."

[Researcher]: *"...Sê nou jy is saam met 'n ander vrou wat van dieselfde dinge hou as jy in die prentjie? Wat sal sy dan wees? 'n Vriendin..."*

[Researcher: "...Say for example you are with another woman in the picture that likes the same things than you? What would she be?. A friend..."

[Researcher]: *"...Wat sou julle sê vertel hierdie prentjie? ('n paartjie wat lag en hande vashou) Liefdesverhouding..."*

[Researcher: "...What would you say this picture tells?..."(a couple holding hands) "...a romantic relationship..."

[Researcher]:["...handed out parcels for every participant..."

[Contents of parcels: large paper clip, fridge magnet, pen made from plastic, treat.]

[Researcher asked participants to remove fridge magnet from parcel. A magnet sometimes represents our relationships, family, friends, strangers, romantic relationships.]

[Researcher]: ["...What type of touch would you say takes place in a romantic relationship?..." "..."Dis baie close..."

[Researcher: "...Now remove the paper clip from you parcel. If you hold the magnet and paperclip close to each other, what happens? They stick together, so that is more like a romantic relationship..."

[Researcher:] "...You and your boyfriend?..."

[Researcher: "...Will you and your female friend be the same as the magnet and the paperclip?" An overall "NO"]

[Researcher: "...Now remove the pen from your parcel..."]

[Researcher: "...Put the paperclip away. Try and attach the pen to the magnet. Do they stick to each other? An overall "NO".]

[Researcher: "....So this is more how friends will be. So touch is different between friends. Say for example you are friends with a male, is there a difference between being friends with a male and having a romantic relationship with him? Overall, "YES".]

[Researcher: "...And a stranger?" What would it be like, the same as..."the magnet and the pen!..."]

[Researcher:] *"...Wat dink julle is belangrik in 'n liefdesverhouding?..."*

[Researcher: "...What do you think is important in a romantic relationship?..."]

- *"...Moet mekaar kan vertrou..."*
- ["...You must be able to trust each other..."]
- *"...Moenie vir mekaar goed wegsteek nie..."*
- ["...Do not hide things from each other..."]
- *"...Moet eerlik wees met mekaar en moet mekaar 100% bystaan ten alle tye..."*
- ["...Be honest with each other and stand by each other 100% at all times..."]
- *"....Moet mekaar respekteer..."*
- ["...Must respect each other..."]
- *"...Daar moenie iemand anders in die verhouding wees nie..."*
- ["...There must not be any body else in the relationship..."]
- *"...Vertrou dat die Here by julle staan..."*
- ["...Trust that the Lord will stand by you..."]
- *"...Dinge uitpraat..."*
- ["...Talk things through..."]
- *"...'n Verhouding is nie net seks nie..."*
- ["...a Relationship is not just sex..."]
- *"...'n Verhoudings is saam praat en saam kuier..."*
- ["...a Relationship is having conversations and socializing together..."]
- *"...As hy met my praat moet ek luister en as ek met hom praat moet hy luister..."*
- ["...If he talks to me I must listen and If I talk to him he must listen..."]
- *"...'n Verhouding kom van twee kante af, dit is van gee en neem..."*

- ["...a Relationship comes from both sides, it is about give and take..."]
- "...Julle moet dinge bespreek met mekaar en as julle nie saamstem oor iets nie dan moet jy 'n ander voorbeeld gee waaroor julle saam kan stem..."
- ["...You must discuss things with each other and if you do not agree you must give another example that you can agree upon..."]

"...Mans moet jou nie omkoop nie..."

["...men must not try and bribe you..."]

"...Dis soos ek met C, ek het eendag met hom hard baklei, dis nie reg dat hy sê ek lyk nie elke dag mooi nie, ek probeer nie om myself mooi te maak nie, maar hy moet ook onthou ons meisies kry soveel tyd waarin ons moet opstaan en gaan stort, ek het nie 2 ure elke oggend want ek het om my hare te kam en ek kan dit ook nie doen sonder help en die huismoeder loop rond en sy kyk na die ander meisies ook, so ek het vir hom gesê, party dae kan hy vir my sê ek lyk mooi en as hy wil nie dit sê nie dan is dit reg, moenie voor almal sê ek lyk lelik, dit maak my seer..."

["...It is like with C, I fought hard with him one day, it is not right of him to say that I do not look pretty everyday, I don't try to make myself pretty, but he must also remember, us girls only have so much time to get up in the morning and shower, I do not have 2 hours every morning because I have my hair to comb and I can't to it without getting help from the caregiver and she looks after other girls as well, so I told him, some days he can tell me I look nice and if he does not want to say it, it is fine, don't tell me I look ugly in front of everybody, it hurts me..."]

Question 4

What does sexuality mean to your friend or other women in the center?

Wat dink jy beteken seksualiteit vir jou vriendin of ander vroue in die sentrum?

THEME: Boundaries

RESPONSES

"...Die ding is, van die meisies en seuns weet nie wat beteken seks nie..."

["...The thing is, some of the girls and boys don't know what sex means..."]

[Researcher]: "...Hoekom sal jy so sê?..."

[Researcher: "...Why would you say that?..."]

"...Hier is sterkere meisies en swakere meisies..."

["...Here are strong girls and weak girls..."]

"...Want hulle spring van een na die ander een... môre is hulle by die een, oormôre is hulle by daai een..."

["...Because they jump from one to the next...tomorrow they are with one, and the day after tomorrow with another..."]

"...Of as die 'boyfriend' of 'girlfriend' huistoe gaan dan jôl hulle rond met 'n ander een...of die vrouens jôl rond met die ander mans..."

["...Or if the boyfriend or girlfriend goes home, they fool around with someone else...or the women fool around with other men..."]

"Dis van die meisies, ek skeer nie almal onder een kam nie...maar hier is van die meisies..."

["...It is some of the girls, I am not generalising...but there are some of the girls...."]

"...Wat rond jôl..."

["...that fool around..."]

"...Soos A, B en C wat nou al in lang verhoudings is, ek praat nou nie van hulle nie..."

["...Like A, B and C that have been in long-term relationships, I am not talking about them..."]

Question 3

[How will a training programme help you to understand sexuality better?]

Hoe sal 'n program jou help om seksualiteit beter te verstaan?

THEME: Relationship skills

RESPONSES

[Researcher]: *"...dink julle 'n program oor verhoudings, enige tipe verhoudings, oor hoe om op te tree, verskillende tipe aanrakings, aanrakings wat jou dalk ongemaklik kan laat voel, enige optrede in die publiek, vreemdelinge wat aanmerkings maak, dink julle 'n program kan dalk help om van die mense se gedrag te verbeter?...."*

[Researcher: "...do you think a programme about relationships, any type of relationship, about how to behave, different types of touch, touch that might make you feel uncomfortable, any behaviour in public, strangers who make remarks, do you think a programme will help to improve some of the people's behaviour?..."

"...Ja, ja...."

["...Yes, yes..."]

"...Dit sal hulle 'n bietjie help..."

["...It will help them a little bit..."]

"...Dis rêrig 'n baie goeie idee, rêrig..."

["...It's really a very good idea, really..."]

"...Dan verstaan hulle meer oor hoe hulle moet optree..."

["...Then they can understand better how they are suppose to behave..."]

Question 5

[What do you think is important to teach women in a programme about sexuality?]

Wat dink jy is belangrik om vroue te leer in 'n program oor seksualiteit?

THEME: Romantic relationships and boundaries

RESPONSES

[Researcher]: *"...Wat dink julle sal belangrik wees om in so 'n program te hê, byvoorbeeld, "Ek mag nie 'n verhouding met my oom hê nie, want hy is familie, maar ek mag 'n verhouding hê met Japie". Nog 'n voorbeeld is wanneer 'n vreemdeling kom besigheid doen by die sentrum kan een van die inwoners nie net op die persoon afstorm en hom of haar druk en soen nie. So wat dink julle sal belangrik wees in 'n program? Wat dink julle moet die inwoners leer wat hulle gedrag sal verbeter?..."*

[Researcher: "...What do you think would be important to have in such a programme, for example," I am not allowed to have a romantic relationship with my uncle, because he is family, but I can have a relationship with Japie". Another example is when a stranger comes to the centre for business purposes one of the residents can't just run up to him and hug and kiss him. So what do you think would be important to be in such a programme? What do you think the residents should learn that will improve their behaviour?..."]

[Researcher:] *"...Waarvan wil julle meer leer?..."*

[Researcher: "...What would you like to learn more about? ..."]

- *"...Wat is die verskil tussen ander verhoudings en liefdesverhoudings..."*
- ["...What is the difference between other relationships and romantic relationships..."]
- *"...Hoe om op te tree in 'n verhouding..."*
- ["...How to behave in a relationship..."]
- *"...Hoe moet die ou teenoor jou op tree..."*
- ["...How must the guy behave towards you..."]
- *"...Hoe moet die meisie teenoor die ou op tree..."*
- ["...How must the girl behave towards the guy?..."]

[Researcher]: *"...Sou julle sê wat mag jy dan toelaat in 'n verhouding? "...Ja..."*

[Researcher: "...Would you then say what is allowed in a relationship?...Yes..."]

"...Dink julle dat julle partykeer te veel toelaat in 'n verhouding? Ja..."

[Researcher: "...Do you think that you allow too much in a relationship sometimes? Yes..."]

"...Hulle misbruik ons..."

["...They abuse us..."]

[Researcher]: *"...Misbruik in watter opsig?..."*

[Researcher: "...Abuse in what way?..."]

"...Deur seks..."

["...Through sex..."]

[Researcher:] "...Is julle dan dalk bang julle verloor hom? Ja..."

[Researcher: "...Are you perhaps scared you might loose him? Yes..."]

[Researcher:] "...Voel julle dalk jy is bang om alleen te wees? Baie kere..."

[Researcher: "...Do you feel afraid to be alone? Often..."]

[Researcher:] "...Omdat jou familie ver is? Ja..."

[Researcher]: "...Because your family are far away? Yes..."]

[Researcher:] "...Omdat jy al voorheen seergemaak is?"

[Researcher: "...Because you have been hurt previously?..."]

"...In my vorige verhouding het ek baie seergekry want die ou het my net gebruik vir seks en geld en ek het maar aangehou en aangehou totdat hy toe uit die sentrum uit is..."

["...In my previous relationship I got very hurt because the guy only used me for sex and money and I carried on and on until he left the centre..."]

"...Ek was voorheen getroud gewees voor ek in die sentrum in gekom het en die man met wie ek getroud was het my ook maar net misbruik...hy het vir my gesê hy gaan werk en in die 'meantime' het hy by 'n vrou in 'n woonstel gebly en goed, op die einde toe ons egskeiding verby is toe trou hy net na die egskeiding met die vrou want sy het van hom 'n babatjie verwag..."

["...I was married previously before I came to the centre and the man I was married to also just abused me... he told me he was going to work but in the meantime he stayed with another women in a flat and stuff and at the end when our divorce was over he married the other women because she was pregnant with his baby..."]

"...Maar is dit nie omdat daar vrouens is wat nie kan kinders kry nie, dan soek die man nou 'n kind..."

["...Is this not why some women can't have children, then the male wants a child..."]

"...Dan gaan slaap hy rond by ander vrou...ja want hy het geweet dat ek nie kan kinders hê nie..."

[...Then he goes and sleeps around with another woman... yes, because he knows you can't have children..."]

"...Soos die sentrum seuns...meeste van hulle weet die meisies kry die inspuiting..."

[...like the centres boys...most of them know the girls get the injection..."]

"...En van hulle was vir operasies... 'n histerektomie... van die meisies kry die depo inspuiting..."

["...and some of them have been for operations... a historectomy.... some of the girls get the depo..."]

Question 6

What do you think should not be taught to women in a program on sexuality?

Wat dink jy moet nie vir vroue geleer word in 'n program oor seksualiteit nie?

THEME: Content of training programme

RESPONSES

[Researcher:] *Wat dink julle moet nie in so 'n program wees nie? Wat dink julle sal meer konflik of problem veroorsaak? Wat sal julle verkies om nie oor te praat nie?*

[Researcher:] What do you think has to be included in such a programme? What do you think will cause more conflict than problems? What would you prefer not to talk about?

"...Daar moet elke 2 of 3 maande iemand kom om daaroor te praat, veral met die wat nie weet waaroor dit gaan nie..."

["...Every two or three months somebody must come and talk about it, especially with those that do not know what it is about..."]

"...Hulle moet gevat word en gewys word hoe lyk daai mense wat daai siekte het (HIV/AIDS) dat hulle kan sien (Fliëk)..."

["...They must be taken to be shown what those people look like that has that illness (HIV/AIDS) so that they can see (Movie)"]

"...Hulle dink ander mense kry dit nie hulle nie..."

["...They think only other people can get it..."]

"...Om vir jou eerlik te se gelukkig is hier nog nie meisies wat lesbians is nie..."

["...But to tell you honestly, luckily there aren't any girls that are lesbians yet..."]

"...Maar hier is mans wat..." (a lot of giggling and laughing)

["...But there are men here that..." (a lot of giggling and laughing)]

"...Hulle moet my net uit los..."

["...They must just leave me alone..."]

"...Ek en M het complicated relationships...wat maak jy as jy nie 'n boyfriend het nie, want voor C het ek 'n meisie gehad...dit was baie sexual, my ma het vir my gese wees eerder straight of 'n lesbian en vir my was dit anderste, ek het van mans en vrouens gehou...is dit gevaarlik?..."

["...M and I have complicated relationships..." what do you do if you do not have a boyfriend? Before C I had a girlfriend...it was very sexual, my mother told me I must rather be straight or a lesbian and for me it was different, I liked men and women...is it dangerous?..."]

"...Is daar mense wat reg kom? Mense wat gay was wat nie meer gay wil wees nie?..."

["...Are there people come come right? People whom are guy that don't want to be guy anymore?..."]

Question 2

What is important about relationships that you saw in the movie for women?
Wat is belangrik oor verhoudings wat julle in die fliëk gesien het?

THEME: Social Story Movie

RESPONSES

"...Hulle het goeie verhoudings gehad, hulle het goeie tye gehad en slegte tye gehad..."

["...They had good relationships, they had good times and bad times..."]

"...Hulle het deur alles bymekaar gestaan..."

["...They stood by each other through everything..."]

"...Saam gelag, saam gekuier..."

["...They laughed together and they socialized together..."]

"...Saam gehuil..."

["...They cried together..."]

"...Hulle het nie die kind weggestoot toe haar kerel met haar uitgemaak het nie, hulle het mekaar ondersteun..."

["...The didn't push the child aside when her boyfriend left her,...they supported each other..."]

[Researcher]: "...Dink julle dit is dieselfde hier of verskil dit?..."

[Researcher]: "...Do you think that it is the same or does it differ?..."]

"...Party mense sal by my staan en ander sal jou verstoot..."

["...Some people will stand by me and others will push you aside..."]

"...Dis soos ek en M en G, ek sal by hulle staan wanneer hulle deur 'n moeilike tyd gaan want dit is wat vriendinne doen, maar daar is party van hulle wat nie omgee nie wat net sal wegloop, of as jy huil en jy het probleme in jou verhouding en jy fight en jy gaan praat met 'n persoon en dan sal baie van hulle jou net verstoot en se dis nie my besigheid nie en dan verstoot hulle jou..."

["...It is like me and M and G, I will stand by them and when they go through a difficult time, because that is what friends do, but there are some of them that don't care that just walk away, or if you are crying and you have problems and you are fighting in your relationship and you go and talk to that person then others will push you aside and say that it is none of their business and then they push you aside..."]

"...Maar hoe help 'n mens so 'n persoon?..."(1h45min)

["...But how do you help such a person?..."]

[Participant 1: "...To be sexually active..."]

"...Wat beteken die woord "seksualiteit vir jou?..."

SUMMARY

How sexuality was constructed by the caregivers that participated in Focus group 2 contrasted with what was evident during the discussion with the women with intellectual disabilities. Firstly, the women conveyed to understand their own personal values within a romantic relationship as well as what their personal needs were. The following needs were identified, by the women as a collective group what they would want from a training programme teaching them social skills about healthy relationships:

THEME: Similarities and differences in types of relationships

What is the difference between other relationships and romantic relationships?

THEME: Appropriate behaviour

How to behave in a romantic relationship?

What is acceptable behaviour for a man in a romantic relationship?

What is acceptable for a woman in a romantic relationship?

THEME: Acceptable behaviour (boundaries)

What is allowed in a romantic relationship?

What is not allowed in a romantic relationship?

Possible themes delineated from focus group discussions for training programme using social stories:

- Green light (Healthy) vs. Red light (Unhealthy relationships);
- Good touch vs. bad touch;
- Dating
- Friendship
- Personal space
- Relationship sequencing

APPENDIX E: ASSENT FORM IN SYMBOL FORMAT



Faculty of Humanities

22 November 2012

Individual Assent letter

Title:

The sexuality knowledge of women with intellectual disability: A social story approach.

My name is Liezel Rathbone and I would like you to be part of a study that I am doing. I am studying further at the University of Pretoria.

What is the study about?

I would like to know what you have to say about having boyfriends and going on dates. I would also like to know what you think about being a woman and what you talk about with your friends.

What will you be asked to do?

If you say you want to be part of this study, I will ask you to be part of a group and talk to you for about 45 minutes at the centre. If you want to talk to me, you have to tell your parents that you want to talk to me.

What do I have to do?

I will come and visit you at the centre. I will talk to you about your friendships, dating, knowing the difference between public and private places, body rights, types of relationships, dating and other social skills. I will ask you questions about what you know. The questions I ask are private information and I will not talk to other people about that.

Will you be in danger during the study?

You will not be hurt or asked to do anything that you do not want to do. You may feel shy or strange when you talk about boyfriends or going on dates. If you feel too shy, you can stop. If you would like me to help you with these feelings, I will make a plan to help you.

How can the things you say be of any help?

You will be helping me and you and your friend's parents and caregivers will be helped to understand what you think about relationships between boys and girls going on dates and other social activities. You will be able to help me develop a program so that I can help other people know what you think about the things we talked about.

Where and how will the information be kept?

Your voice will be recorded with this little machine (*show digital voice recorder and demonstrate*). Only I will listen to it to help me remember what you said. I am going to give you a number so that I don't use your name when I write about the things you told me. I will type what you have said on a computer. Nobody will be able to go onto my computer because only I have the number for the computer.

Centre for Augmentative and Alternative
Communication, Room 2-36, Corn path
Building, Lynnwood Road
University of Pretoria, Private Bag X20
Hatfield 0028, South Africa
Tel +27 (0)12 420 2001
Fax +27 (0) 86 5100841
Email saak@up.ac.za
www.caac.up.ac.za

Fakulteit Geesteswetenskappe
Lefapha la Bomotheo

Can you stop at any time?

You can decide to talk to me or you can say that you do not want to be in this study. If at any time you feel that you do not want to talk to me anymore you can tell me that you want to stop. I will not be angry. It is OK to say that you want to stop at anytime.

What are your rights?

Do you understand the information letter that I read to you to explain what today is all about?

Do you understand that it is your choice to help me today?

Do you understand that you can stop anytime you want to?

Do you understand that I will be using a tape recorder today?

Do you have any questions?

Do you understand the answers I have given you?

Are you happy to help me today?

Is there anything you do not understand?

Thank you for helping me!





This form will be completed together with the researcher during the individual administration sessions.

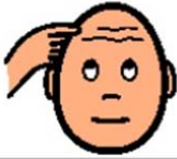

For office use only

Participant number:

--	--	--

Name of participant: _____

	<p>Do you understand the information letter that I read to you and did I explain what today is all about?</p> <p style="text-align: center;">YES NO</p>
	<p>Do you understand that it is your choice to help me today?</p> <p style="text-align: center;">YES NO</p>
	<p>Do you understand that you can stop anytime you want to?</p> <p style="text-align: center;">YES NO</p>
	<p>Do you understand that I will be using a tape recorder today?</p> <p style="text-align: center;">YES NO</p>
	<p>Do you have any questions?</p> <p style="text-align: center;">YES NO</p>

	<p>Do you understand the answers I have given you?</p> <p>YES NO</p>
	<p>Are you happy to help me today?</p> <p>YES NO</p>

Signed by participant: _____

Liezel Rathbone
Researcher
PhD Student
University of Pretoria
Centre for AAC

Prof Juan Bornman
Supervisor

APPENDIX F: COMPLETE MEASURING INSTRUMENT

MEASURING INSTRUMENT

Complete ALL questions. Mark your answer with an (x) in the most relevant block. Thank you for your time.

 For office
 Use only

1. Participant number	V1	<input type="checkbox"/>
2. How old are you?years	V2	<input type="checkbox"/>
3. What is your home language? (Mark all; you may mark more than 1).	V3	<input type="checkbox"/>
English		<input type="checkbox"/>
Afrikaans		<input type="checkbox"/>
SeTswana		<input type="checkbox"/>
SeSotho		<input type="checkbox"/>
IsiZulu		<input type="checkbox"/>
Other(Specify)		<input type="checkbox"/>
4. What is your religious affiliation?	V4	<input type="checkbox"/>
Christian		<input type="checkbox"/>
Islam		<input type="checkbox"/>
Hindu		<input type="checkbox"/>
Judaism		<input type="checkbox"/>
None		<input type="checkbox"/>
Other: (please specify)		<input type="checkbox"/>
5. How often do you attend church related activities?	V5	<input type="checkbox"/>
More than once a week		<input type="checkbox"/>
Once a week		<input type="checkbox"/>
Once a month		<input type="checkbox"/>
On special occasions		<input type="checkbox"/>
Never		<input type="checkbox"/>
6. How long have you been working at this residential care facility?years	V6	<input type="checkbox"/>

7. In total, how many of your working hours per day that is implied do you interact with the women with intellectual disability?

V7

2 hours or less	
4 hours	
6 hours	
8 hours or more	

8. Have you ever spoken to the women with intellectual disability about sexuality?

V8

Yes	
No	

9. Do you know if there are women with intellectual disability who have been exposed to sexuality education training programs before?

V9

Yes	No	Unsure
-----	----	--------

10. Are you aware if there is an existing sexuality policy at the residential care facility?

V10

Yes	No	Unsure
-----	----	--------

11. Do you support a sexuality policy?

V11

Yes	No	Unsure
-----	----	--------

12. Women with intellectual disabilities should know that there are different ways to touch strangers and familiar people

True	False
------	-------

V12

13. It is important for women with intellectual disabilities to understand non-verbal behavior..

True	False
------	-------

V13

14. Women with intellectual disabilities have a greater need for touch than women without intellectual disabilities.

True	False
------	-------

V14

15. Women with intellectual disabilities should know that it is appropriate to greet a stranger with a handshake.

True	False
------	-------

V15

16. Women with intellectual disabilities have difficulty understanding the boundaries between "private" and "public".

True	False
------	-------

V16

17. Women with intellectual disabilities do not know when they are unsafe in a relationship.

True	False
------	-------

V17

18. Women with intellectual disabilities like to be touched by anybody.

True	False
------	-------

V18

19. Women with intellectual disability should know how to start appropriate conversations.

True	False
------	-------

V19

20. Women with intellectual disability understand that some secrets make them "happy" and some secrets make them "unhappy".

True	False
------	-------

V20

21. Caregivers should teach women with intellectual disabilities how to label new information as "public" or "private".

True	False
------	-------

V21

22. Women with intellectual disabilities should know that people who want to take advantage of them will ask them to keep secrets about sexual things.

True	False
------	-------

V22

23. Teaching women about relationships involves teaching them about social skills.

True	False
------	-------

V23

24. In relationships it is important how to greet appropriate in different situations.

True	False
------	-------

V24

25. Caregivers are people who get paid to help and assist and support the women with intellectual disabilities they care for.

True	False
------	-------

V25

26. Caregivers may have feelings for the women with they take care of.

True	False
------	-------

V26

27. Caregivers need to teach women with intellectual disabilities the difference between good and bad relationships.

True	False
------	-------

V27

28. Women with intellectual disabilities should know that the person they are interested in should not be related to them.

True	False
------	-------

V28

29. It is okay for caregivers to touch women in a sexual way.

True	False
------	-------

V29

30. Women with intellectual disabilities should be able to have relationships with the opposite sex.

True	False
------	-------

V30

31. Romantic relationships are when two people have sexual feelings for each other.

True	False
------	-------

V31

32. Women with intellectual disabilities should know that the individuals that they are interested in should not be related to them.

True	False
------	-------

V32

33. Romantic relationships are when two people have sexual feelings for each other.

True	False
------	-------

V33

34. Teaching women with intellectual disabilities to have appropriate conversations can help them feel more comfortable in their relationships.

True	False
------	-------

V34

35. Sexuality education will empower women to make responsible choices..

True	False
------	-------

V35

36. A sexuality education program will result in more sexual activity.

True	False
------	-------

V36

37. Women with intellectual disabilities' understanding of their sexuality are important for their self-image.

True	False
------	-------

V37

38. Women with intellectual disabilities are sterile.

True	False
------	-------

V38

39. Women with intellectual disabilities are oversexed.

True	False
------	-------

V39

40. Women with intellectual disabilities are more vulnerable to sexual abuse and exploitation than women that do not have an intellectual disability..

True	False
------	-------

V40

41. Women with intellectual disabilities often engage in sexual behavior.

True	False
------	-------

V41

42. Women with intellectual disabilities are asexual (they have no sexual needs).

True	False
------	-------

V42

43. Women with intellectual disabilities experience puberty later than their peers..

True	False
------	-------

V43

44. Sexuality involves social aspects.

True	False
------	-------

V44

45. Sexuality involves having a relationship with someone.

True	False
------	-------

V45

46. Touch is an essential part of human life.

True	False
------	-------

V46

47. Women with intellectual disabilities touch others inappropriately because of social isolation.

True	False
------	-------

V47

48. Women with intellectual disabilities should be encouraged to have romantic relationships.

True	False
------	-------

V48

49. Sexuality and relationship education will empower women with intellectual disabilities to make responsible choices.

True	False
------	-------

V49

50. Women with intellectual disability have a right to sexuality education.

True	False
------	-------

V50

APPENDIX G: COMPLETE TRAINING EVALUATION FORM

TRAINING EVALUATION FORM

Thank you for your commitment and participation. I greatly appreciate your feedback. Please look at each statement below, and put an X to show if you agree or disagree or are unsure about each of the following statements regarding the training that you received.

For office
use only

1. PARTICIPANT NUMBER				V1 <input type="text"/>
2. PRESENTATION OF THE TRAINING				
	Agree	Unsure	Disagree	
The trainer was well prepared for the training.				V2 <input type="text"/>
The training sessions were logically planned and presented.				V3 <input type="text"/>
The length of the training was sufficient.				V4 <input type="text"/>
The training will definitely be useful for our care facility as well as others.				V5 <input type="text"/>
There were enough opportunities for participation during training.				V6 <input type="text"/>
The training will help me explain sexuality to the women in my care.				V7 <input type="text"/>
I will recommend this training to other caregivers who work with women with intellectual disabilities.				V8 <input type="text"/>
The training material is easy to use.				V9 <input type="text"/>
The terminology used in the training program is easy to understand.				V10 <input type="text"/>
The instructions are easy to follow in the training program.				V11 <input type="text"/>
The activities of each theme are appropriate and easy to do.				V12 <input type="text"/>
The teaching aids are relevant and enhanced my understanding of sexuality and relationships.				V13 <input type="text"/>
The social stories are easy to read.				V14 <input type="text"/>
The social stories are disability friendly.				V15 <input type="text"/>
The most important information about sexuality and relationship education training is captured in the programme.				V16 <input type="text"/>

<p>3. OVERALL RATING OF TRAINING SESSION (Mark with an X)</p> <table border="1" style="margin: 10px auto; border-collapse: collapse; text-align: center;"> <tr> <td style="width: 20%;">1</td> <td style="width: 20%;">2</td> <td style="width: 20%;">3</td> <td style="width: 20%;">4</td> <td style="width: 20%;">5</td> </tr> <tr> <td>Very poor</td> <td>Poor</td> <td>Average</td> <td>Good</td> <td>Very Good</td> </tr> <tr> <td> </td> <td> </td> <td> </td> <td> </td> <td> </td> </tr> </table> <p>4. COMMENTS AND SUGGESTIONS FOR FURTHER TRAINING</p> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <p>5. WHICH 3 ASPECTS OF THE TRAINING DID YOU ENJOY MOST?</p> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>	1	2	3	4	5	Very poor	Poor	Average	Good	Very Good						<div style="border: 1px solid black; width: 40px; height: 20px; margin: 10px auto; display: flex; align-items: center; justify-content: center;">V17</div> <div style="border: 1px solid black; width: 40px; height: 20px; margin: 10px auto; display: flex; align-items: center; justify-content: center;">V18</div> <div style="border: 1px solid black; width: 40px; height: 20px; margin: 10px auto; display: flex; align-items: center; justify-content: center;">V19</div>
1	2	3	4	5												
Very poor	Poor	Average	Good	Very Good												

Appendix H: Permission from Director for Pilot Study 1



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Faculty of Humanities



29 July 2014

De: [Redacted]

REQUEST TO CONDUCT RESEARCH AT YOUR ORGANIZATION

I am a final year PhD student at the University of Pretoria. In partial fulfillment for the requirements of this degree I am requested to conduct a research project.

I hereby request permission to conduct my proposed research study at your organization.

Research topic: The effect of a training program on the knowledge and attitudes of caregivers of women with intellectual disabilities, related to sexuality issues.

Rationale for the study:

The rationale for this study is to present a sexuality and relationship education training program for caregivers in order to equip them with the necessary knowledge and skills to support women with intellectual disabilities. The program will introduce concepts such as appropriate behaviour in public and private places, the ability to differentiate between different types of relationships, appropriate and inappropriate touching and personal space. The training program is primarily aimed at caregivers of women with intellectual disabilities and therefore focuses on the foundation work necessary to teach sexuality education.

The premise of this training program is that sexuality education will provide caregivers with an opportunity to equip women with intellectual disabilities with protective behaviours. Adult women with intellectual disabilities may need more education and support because of their increased risk and vulnerability in a variety of situations, including sexual abuse and exploitation. Reasons for women with intellectual disabilities' increased vulnerability to sexual abuse and exploitation include the following:

1. Their lack of knowledge and limited prior education concerning sexuality issues;
2. Their reliance on their sexuality education from non-experts such as their peers, internet (or cell phones or computers), television and other media resources such as magazines or a variety of untrained individuals who may or may not have their best interests at heart;
3. Their difficulty retaining information when certain teaching methods are used;
4. Their heightened trust in others due to increased dependence for assistance;
5. Their lack of assertiveness skills and their inability to say "NO";

Centre for Augmentative and Alternative Communication (CAAC)
Sentrum vir Aanvullende en Alternatiewe Kommunikasie (SAAK)
Communication Pathology Building
University of Pretoria, Lynnwood Road
PRETORIA, 0002
Republic of South Africa

Fax/Faks: +27 86 510 0841
Tel: +27 12 420 2001

juan.bornman@up.ac.za
www.caac.up.ac.za

Therefore, the importance of empowering caregivers with relevant knowledge and skills cannot be highlighted enough. This will also help them to dispel the commonly held myths regarding sexuality which generally stem from ignorance, limited experience or narrowly defined views of what sexuality and relationship education entails. We realize the need for increased information in this regard as well as guidance and support to empower the caregivers.

What are the aims of this study?

The primary aim of this study is to describe the effect of a 2-day custom designed sexuality and relationship education training program on the attitudes and knowledge of caregivers of women with intellectual disabilities, regarding their sexuality, by using a particular teaching strategy, namely social stories.

What is the main-aim of the study?

To describe the effect of a 2-day custom designed sexuality and relationship education training program on the attitudes and knowledge of caregivers of women with intellectual disabilities, regarding their sexuality using social stories.

What are the sub-aims of the study?

- i) To measure the attitudes and knowledge of caregivers of women with intellectual disabilities, regarding sexuality, related to the following aspects: appropriate and inappropriate touching, dating, public and private places, different types of relationships, and sexuality education;
- ii) To develop and implement a sexuality and relationship education training program with caregivers to address sexuality related to the aspects mentioned in sub-aim 1;
- iii) To measure attitudes and knowledge of caregivers after implementation of the sexuality and relationship education training program;
- iv) To compare the pre-test and post-test measures in order to describe the effect of the sexuality and relationship education and training program.

What will be expected of your organization?

Upon providing consent you will grant me permission to conduct a pilot study using the caregivers at your group home. This will assist me in the refinement of a sexuality and relationship education training program for caregivers of women with intellectual disabilities using social stories.

Will you have access to the research results?

The research results will be made available upon request following the completion of the project. The research data will be stored both as hard copy as well as in electronic format at the University of Pretoria for 15 years as part of the ethical requirements of the University. Results may also be shared with other professionals in article or conference presentation format.

I trust that this letter has provided you with sufficient information as to allow you to grant me permission to conduct the proposed study at your institution.

Attached is a copy of the ethical approval from the University of Pretoria ensuring that this research project adheres to the strict ethical requirements set by die University.

Centre for Augmentative and Alternative Communication (CAAC)
Sentrum vir Aanvullende en Alternatiewe Kommunikasie (SAAK)
Communication Pathology Building
University of Pretoria, Lynnwood Road
PRETORIA, 0002
Republic of South Africa

Fax/Faks: +27 86 510 0841
Tel: +27 12 420 2001

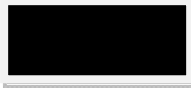
juan.bornman@up.ac.za
www.caac.up.ac.za

Should you require any further information, you are welcome to contact me at [REDACTED] or at the following e-mail address: [REDACTED]

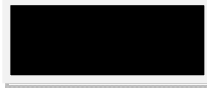
Please inform me in writing of your decision.

Yours sincerely

Liezel Rathbone
Researcher



Prof Juan Bornman
Supervisor



Centre for Augmentative and Alternative Communication (CAAC)
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APPENDIX I: PHOTO COLLAGE OF PILOT STUDY 1

PILOT STUDY 1



APPENDIX J: INFORMATION LETTER FOR REGIONAL DIRECTOR OF SOCIAL DEVELOPMENT NETWORK



Director:

1 December 2014

Dear Ms _____

RE: REQUEST TO CONDUCT RESEARCH AT A FACILITY IN YOUR NETWORK

I am a final year PhD student at the University of Pretoria. In partial fulfilment for the requirements of this degree I am requested to conduct a research project.

I hereby request permission to conduct my proposed research study at a facility in your network.

Research topic: The effect of a sexuality training programme on the knowledge and attitudes of caregivers working with women with intellectual disabilities: A social story approach

Rationale for the study:

The rationale for this study is to present a sexuality and relationship education training program for caregivers in order to equip them with the necessary knowledge and skills to support women with intellectual disabilities. The program will introduce concepts such as appropriate and inappropriate touching, privacy and inappropriate conversations, the ability to differentiate between different types of relationships, romantic relationships and other social skills. The training program is primarily aimed at caregivers of women with intellectual disabilities and therefore focusses on the foundation work necessary to teach sexuality education.

The premise of this training program is that sexuality education will provide caregivers with an opportunity to equip women with intellectual disabilities with protective behaviours. Adult women with intellectual disabilities may need more education and support because of their increased risk and vulnerability in a variety of situations, including sexual abuse and exploitation. Reasons for women with intellectual disabilities' increased vulnerability to sexual abuse and exploitation include the following:

1. Their lack of knowledge and limited prior education concerning sexuality issues;
2. Their reliance on their sexuality education from non-experts such as their peers, internet (or cell phones or computers), television and other media resources such as magazines or a variety of untrained individuals who may or may not have their best interests at heart;
3. Their difficulty retaining information when certain teaching methods are used;
4. Their heightened trust in others due to increased dependence for assistance;
5. Their lack of assertiveness skills and their inability to say "NO";

Therefore, the importance of empowering caregivers with relevant knowledge and skills cannot be highlighted enough. This will also help them to dispel the commonly held myths regarding sexuality which generally stem from ignorance, limited experience or narrowly defined views of what sexuality

and relationship education entails. We realize the need for increased information in this regard as well as guidance and support to empower the caregivers.

What are the aims of this study?

The primary aim of this study is to describe the effect of a 2-day custom designed sexuality and relationship education training program on the attitudes and knowledge of caregivers of women with intellectual disabilities, regarding their sexuality, by using a particular teaching strategy, namely social stories.

What will be expected of your network?

Upon providing consent you will grant me permission to recruit a residential care facility for women with intellectual disabilities from your network with your assistance. This will assist me to identify possible participants.

Will you have access to the research results?

The research results will be made available upon request following the completion of the project. The research data will be stored both as hard copy as well as in electronic format at the University of Pretoria for 15 years as part of the ethical requirements of the University. Results may also be shared with other professionals in article or conference presentation format.

I trust that this letter has provided you with sufficient information as to allow you to grant me permission to conduct the proposed study at your institution.

Attached is a copy of the ethical approval from the University of Pretoria ensuring that this research project adheres to the strict ethical requirements set by die University.

Should you require any further information, you are welcome to contact me at [redacted] or at the following e-mail address: [redacted]

Please inform me in writing of your decision.

Yours sincerely

Liezel Rathbone
Researcher

[redacted]

Prof. Juan Bornman
Supervisor

[redacted]

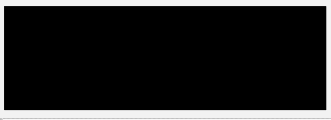
APPENDIX K: PHOTO COLLAGE OF MAIN STUDY TRAINING



APPENDIX L: REQUEST LETTER TO DIRECTOR AT RESIDENTIAL CARE FACILITY FOR MAIN STUDY



Faculty of Humanities



1 December 2014



RE: REQUEST TO CONDUCT RESEARCH AT YOUR ORGANIZATION

I am a final year PhD student at the University of Pretoria. In partial fulfilment for the requirements of this degree I am requested to conduct a research project.

I hereby request permission to conduct my proposed research study at your organization.

Research topic: The effect of a training program on the knowledge and attitudes of caregivers of women with intellectual disabilities, related to sexuality issues.

Rationale for the study:

The rationale for this study is to present a sexuality and relationship education training program for caregivers in order to equip them with the necessary knowledge and skills to support women with intellectual disabilities. The program will introduce concepts such as appropriate and inappropriate touching, privacy and inappropriate conversations, the ability to differentiate between different types of relationships, romantic relationships and other social skills. The training program is primarily aimed at caregivers of women with intellectual disabilities and therefore focusses on the foundation work necessary to teach sexuality education.

The premise of this training program is that sexuality education will provide caregivers with an opportunity to equip women with intellectual disabilities with protective behaviours. Adult women with intellectual disabilities may need more education and support because of their increased risk and vulnerability in a variety of situations, including sexual abuse and exploitation. Reasons for women with intellectual disabilities' increased vulnerability to sexual abuse and exploitation include the following:

Their lack of knowledge and limited prior education concerning sexuality issues;
Their reliance on their sexuality education from non-experts such as their peers, internet (or cell phones or computers), television and other media resources such as magazines or a variety of untrained individuals who may or may not have their best interests at heart;

1. Their difficulty retaining information when certain teaching methods are used;

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Communication, Room 2-36, Com path
Building, Lynnwood Road
University of Pretoria, Private Bag X20
Hatfield 0028, South Africa
Tel +27 (0)12 420 2001
Fax +27 (0) 86 5100841
Email saak@up.ac.za
www.caac.up.ac.za

Fakulteit Geesteswetenskappe
Lefapha la Bomotho

2. Their heightened trust in others due to increased dependence for assistance;
3. Their lack of assertiveness skills and their inability to say "NO";

Therefore, the importance of empowering caregivers with relevant knowledge and skills cannot be highlighted enough. This will also help them to dispel the commonly held myths regarding sexuality which generally stem from ignorance, limited experience or narrowly defined views of what sexuality and relationship education entails. We realize the need for increased information in this regard as well as guidance and support to empower the caregivers.

What are the aims of this study?

The primary aim of this study is to describe the effect of a 2-day custom designed sexuality and relationship education training program on the attitudes and knowledge of caregivers of women with intellectual disabilities, regarding their sexuality, by using a particular teaching strategy, namely social stories.

What will be expected of your organization?

Upon providing consent you will grant me permission to conduct the proposed research study using the caregivers at your group home. This will assist me to identify possible participants. Furthermore, you will also be granting me permission to use your premises as the main site for the 2-day training.

Will you have access to the research results?

The research results will be made available upon request following the completion of the project. The research data will be stored both as hard copy as well as in electronic format at the University of Pretoria for 15 years as part of the ethical requirements of the University. Results may also be shared with other professionals in article or conference presentation format.

I trust that this letter has provided you with sufficient information as to allow you to grant me permission to conduct the proposed study at your institution.

Attached is a copy of the ethical approval from the University of Pretoria ensuring that this research project adheres to the strict ethical requirements set by die University.

Should you require any further information, you are welcome to contact me at [redacted] or at the following e-mail address: [redacted]

Please inform me in writing of your decision.
Yours sincerely

Liezel Rathbone
Researcher

Prof. Juan Bornman
Supervisor

[redacted]

APPENDIX M: CONSENT LETTER FROM PARTICIPANTS FOR MAIN STUDY



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities

29 July 2014

CAREGIVER INFORMED CONSENT LETTER

I am a PhD student at the University of Pretoria. In partial fulfillment for the requirements of this degree I am requested to conduct a research project.

Research topic: The effect of a 2-day custom designed training program on the knowledge and attitudes of caregivers of women with intellectual disabilities, related to sexuality issues.

Rationale for the study:

The purpose of this study is to develop and implement a training program for caregivers of women with intellectual disabilities.

Rationale for the study:

The rationale for this study is to present a sexuality and relationship education training program for you in order to equip you with the necessary knowledge and skills to support women with intellectual disabilities. The program will introduce concepts such as appropriate behaviour in public and private places, the ability to differentiate between different types of relationships, appropriate and inappropriate touching and personal space. The training program is primarily aimed on the foundation work necessary to teach women with intellectual disability sexuality education.

The premise of this training program is that sexuality education will provide you with an opportunity to equip women with intellectual disabilities with protective behaviours. Adult women with intellectual disabilities may need more education and support because of their increased risk and vulnerability in a variety of situations, including sexual abuse and exploitation. Reasons for women with intellectual disabilities' increased vulnerability to sexual abuse and exploitation include the following:

1. Their lack of knowledge and limited prior education concerning sexuality issues;
2. Their reliance on their sexuality education from non-experts such as their peers, internet (or cell phones or computers), television and other media resources such as magazines or a variety of untrained individuals who may or may not have their best interests at heart;
3. Their difficulty retaining information when certain teaching methods are used;
4. Their heightened trust in others due to increased dependence for assistance;
5. Their lack of assertiveness skills and their inability to say "NO";

Therefore, the importance of empowering you with relevant knowledge and skills cannot be highlighted enough. This will also help you to dispel the commonly held myths regarding sexuality which generally stem from ignorance, limited experience or narrowly defined views of what sexuality and relationship education entails. We realize the need for increased information in this regard as well as guidance and support to empower you.

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Republic of South Africa

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juan.bomman@up.ac.za
www.caac.up.ac.za

What are the aims of this study?

In this training program we believe that women with intellectual disabilities have the need and the human right to accurate sexuality and relationship education and training, specifically what constitutes appropriate and inappropriate touching, knowing the difference between public and private places, the ability to differentiate between different types of relationships, dating and other social skills.

What is the main-aim of the study?

To describe the effect of a 2-day custom designed sexuality and relationship education training program on the attitudes and knowledge of caregivers of women with intellectual disabilities, regarding their sexuality using social stories.

What are the sub-aims of the study?

- i) To measure the attitudes and knowledge of caregivers of women with intellectual disabilities, regarding sexuality, related to the following aspects: appropriate and inappropriate touching, dating, public and private places, different types of relationships, and sexuality education;
- ii) To develop and implement a sexuality and relationship education training program with caregivers to address sexuality related to the aspects mentioned in sub-aim 1;
- iii) To measure attitudes and knowledge of caregivers after implementation of the sexuality and relationship education training program;
- iv) To compare the pre-test and post-test measures in order to describe the effect of the sexuality and relationship education and training program.

Why is my participation important?

- Your participation in this research project will have no direct benefit to you.
- Your participation in this research project will contribute to the content and development of a sexuality and relationship education training program for caregivers of women with intellectual disabilities.
- You will be asked to participate in a pilot study.
- Participating in this training program confirms that you recognize and accept the fact that sexuality and relationship education is an important part of women with intellectual disability's life and that you regard sexuality and relationships as a positive aspect of being human and acknowledge women with intellectual disabilities needs and human rights to information.

What is expected of me as a participant?

To enable your participation in this pilot study you are requested to complete the *Caregiver Informed Consent Slip*. Please retain this letter for your own use.

I do understand that you have a busy schedule. It would, however, be of great value if you should agree to participate in this study, as both you are highly valued.

Is there any risk or discomfort associated with this study?

You will not be subjected to any risks. The only discomfort that you may experience whilst participating in this study is the sacrifice of your own time attending training.

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www.caac.up.ac.za

As mentioned this training will span over two days. All the information obtained during the study will be handled confidentially. All participants will be assigned a participant number.

Will I have access to the research results?

- The research results will be made available upon request following the completion of the project. The research data will be stored both as hard copy as well as in electronic format at the University of Pretoria for 15 years as part of the ethical requirements of the University. Results may also be shared with other professionals in article or conference presentation format.
- I trust that this letter has provided you with sufficient information as to allow you to grant me permission to conduct the proposed study at your institution.
- Should you require any further information, you are welcome to contact me at 078 1790150 or at the following e-mail address: liezelr@vut.ac.za.

What is expected of me as a participant?

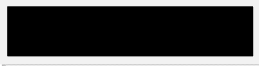
To enable your participation in this study, you are requested to sign the *Staff Informed Consent Letter*.

Kindly e-mail me or deliver by hand, your Informed Consent letter indicating your consent/non-consent to participate in the study. Please retain this information pamphlet for your own use.

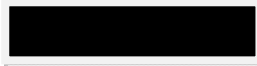
Please inform me in writing of your decision.

Yours sincerely

Liezel Rathbone
Researcher



Prof Juan Bornman
Supervisor



APPENDIX N: ETHICS APPROVAL AND EDITORIAL CHANGE OF TITLE OBTAINED FROM
THE ETHICS COMMITTEE OF THE FACULTY OF HUMANITIES:
UNIVERSITY OF PRETORIA



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

21 April 2015

Dear Prof Bornman

Project: The sexual knowledge of women with mild to moderate intellectual disabilities: a social story approach
Researcher: L Rathbone
Supervisor: Prof J Bornman
Department: Centre for Augmentative and Alternative Communication
Reference number: 26435846 (GW20150425)

Thank you for your response to the Committee's correspondence of 30 May 2011.

I have pleasure in informing you that the Research Ethics Committee formally **approved** the above study at an *ad hoc* meeting held on 20 April 2015. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should your actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely



Prof. Karen Harris
Acting Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: karen.harris@up.ac.za

Research Ethics Committee Members: Prof KL Harris(Acting Chair); Dr L Blokland; Prof M-H Coetzee; Dr JEH Grobler; Prof B Hogmeyer; Ms H Klopper; Dr C Panebianco-Warrens; Dr C Puttergill; Prof GM Spies; Dr Y Spies; Prof E Taljard; Dr P Wood



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Faculty of Humanities

Our Ref: 26435846

16 November 2015

Mrs L Rathbone
Private Bag X20
HATFIELD
0028

Dear Mrs Rathbone

TITLE REGISTRATION : FIELD OF STUDY - PHD AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

I have pleasure in informing you that the following has been approved:

TITLE: The effect of a sexuality training programme on the knowledge and attitudes of caregivers working with women with intellectual disabilities who live in residential care facilities: A social story approach

SUPERVISOR: Prof J Bornman

PLEASE TAKE NOTE OF THE FOLLOWING INFORMATION AS WELL AS THE ATTACHED REQUIREMENTS.

1. **PERIOD:**
 - (a) You must be enrolled as a student for at least one academic year before submission of your thesis.
 - (b) Your enrolment as a student must be renewed annually before 31 March, until you have complied with all the requirements for the degree. You will only be liable to have supervision if you provide a proof of registration to your supervisor.
2. **NOTIFICATION BEFORE SUBMISSION:**

You are required to notify me at least three months in advance of your intention to submit your thesis for examination.
3. **APPROVAL FOR SUBMISSION:**

On completion of your thesis enough copies for each examiner as well as the prescribed examination enrolment form which includes a statement by your promoter that he/she approves of the submission of your thesis, as well as a statement signed by you, must be submitted to Student Administration.
4. **DATE OF EXAMINATION:**

If your doctoral examination is to take place after the submission of your thesis, please inform me of the date of the examination.

Yours sincerely

for DEAN: FACULTY OF HUMANITIES

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Humanities Student Administration
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Email: jana.bezuidenhout@up.ac.za
Website: www.up.ac.za

APPENDIX O: EXAMPLE OF TRAINING CERTIFICATES

Practical Introduction to Sexuality and Relationships



CERTIFICATE OF ATTENDANCE

This is to certify that

Name of Caregiver

Identity number

attended a

**Sexuality and Relationship Education Training Program on the
2nd and 3rd of December 2014**

Date

Trainer: Lizzi Rathbone
Registered Counsellor
PR0001716