

The Current Status of Sex Education Practice For People with an Intellectual Disability in Ireland

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*Commissioned by
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One of the key tasks of service providers in the intellectual disability sector is to promote the independence and autonomy of the individual so that he or she is equipped with skills necessary for self-determination; that is holding the main responsibility for the choices and decisions made regarding one's life. Self-determination is recognised as being of critical importance in perceptions of the meaningfulness and fulfilment that people experience in their lives. However, services are also changed with the responsibility that they do all that is possible to prevent harm befalling a vulnerable child or adult. No where more so are these conflicting demands placed on services and their staff than in the area of relationships and sexuality education. A legislative context which does not recognise the right of persons with intellectual disability to appropriate sexual expression and a shifting social and cultural backdrop are additional facets of the uncertain framework in which we operate.

The Irish Sex Education Network (founded in 2002 and following on the work of the Sex Education Working Group which was active in Ireland in the nineties) has as its primary aim the promotion of high professional standards and best practice in the area of sex education for those with disabilities, with a particular emphasis on people with intellectual disabilities. The research report that follows is the result of our quest to investigate what is actually happening 'on the ground' with regard to sex education practice within the intellectual disability sector. The report also contains a review of international literature towards gaining insight into recommendations for good practice drawn from research and experience abroad. This study is very much illuminatory in nature but the information yielded will, we feel, be of use in helping to identify the needs of service staff, with regard to training, support and ongoing programme development in the area of relationships and sexuality education as well as in providing directions for future research.

We are most grateful to the Sexual Health Centre, Cork, who undertook both the fieldwork and write up of this study, to the National Disability Authority and to the

Crisis Pregnancy Agency whose funding made this research possible and, of course, to all those busy service staff who completed our questionnaire and breathed life into the study.

Catherine Canney
Chairperson
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March 2007

For further information on the Irish Sex Education Network, please see
www.isenonline.com

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Abbreviations

CPA: Crisis Pregnancy Agency

fpaNI: Family Planning Association Northern Ireland

ID: Intellectual Disability

ISEN: Irish Sex Education Network

NDA: National Disability Association

RSE: Relationship and Sexuality Education

SHC: The Sexual Health Centre

SRE: Sexuality and Relationship Education

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Executive Summary

Introduction

Little is known in Ireland about levels of sexual health knowledge among people with intellectual disabilities, staff attitudes towards sexuality, staff training and qualifications to deliver RSE programmes, all of which are important to improve the sexual health of people with intellectual disabilities.

This study aims to capture the current provision of Relationships, Sexuality Education for people with intellectual disabilities in Ireland. Recognition of the sexuality and sexual health education needs of people with intellectual disabilities can be difficult for people who care and work for them. Yet, there has been growing evidence of the need to address these issues, to move outside our comfort zones, so that we respond with integrity and sensitivity to this much neglected area.

In order to contextualise the debate, a literature review was undertaken so as to provide an awareness of the availability of RSE programmes for people with intellectual disability and evidence of best practice. The provision of quality training in RSE involves appropriate training and support for staff and this study identifies the type and extent of staff training as well as their assessment of comfort and competence to deliver such training.

Methods

Self administered questionnaires were sent to 244 individuals working in 152 agencies involved with intellectual disabilities. A total of 151 responses were received using this method. A snowballing technique was encouraged and staff were requested to pass copies of the questionnaire to other colleagues. A further 16 responses were received as a result of this snowballing approach. A total of 14 respondents participated in telephone interviews to provide more in depth, qualitative data.

Results

The research suggests that there is no national structured approach to the provision of RSE to people with intellectual disability. Whatever RSE is provided is piecemeal and many people with an intellectual disability are not receiving it. Staff and carers often feel unprepared to address the sexual health needs of people with intellectual disability. Indeed, there is little evidence of the sexual knowledge or feelings of people with intellectual disability or the effectiveness of educational programmes to alter this knowledge and feelings. The literature review suggests a range of initiatives promoting positive attitudes to sexuality and improving knowledge. RSE should be rights based with language and resources focusing on ability, potential, confidence and self-actualisation rather than disability.

Findings from the survey showed that

- Just over three quarters (78%) of respondents had no in-house training policies in relation to RSE delivery.
- Just under three quarters (71%) of respondents indicated that their service did not provide RSE to its service users. Only a quarter (25%) of respondents reported that some form of RSE was delivered.
- Just over half (57%) stated that training was delivered by in-house trainers. A further 14% indicated that outside agencies delivered the training and 29% used a combination of both inside trainers and outside agencies (see Figure 4.4).
- Of those currently delivering RSE programmes the majority (80%) said they had received some form of training to assist them in delivering programmes. However, the majority of these had undertaken just 1 or 2-day courses.
- Despite the poverty of training opportunities, 28 (90%) of staff who were delivering programmes stated they felt comfortable doing so and 23 (75%) felt competent to do so.

- Considerable interest was expressed in receiving training. 78% of those not currently offering programmes expressing an interest in undertaking training in RSE facilitation, while a further 16% would like to receive information only.
- When asked who was most appropriate to deliver training, 26 % of respondents thought that it should be frontline staff, 39% multi-disciplinary staff and 35% specific RSE trainers.
- A majority of respondents (74%) felt that RSE was important for all their service users. A further 21% felt RSE to be important for some service users. There was a non-response rate of 4%.

Conclusions and Recommendations

- There needs to be increased opportunities for sexual health awareness training for people with intellectual disability which promotes positive attitudes to sexuality, increases confidence and self esteem and which focuses on ability.
- Assistance needs to be provided for parents / carers so that they can provide support and explore their own attitudes and values.
- Resources need to be available for people with intellectual disabilities, staff and parents / carers.
- Training and development opportunities and programmes need to be provided for staff. Evaluation of such programmes needs to be embedded as an essential component of their implementation.
- A national approach needs to be adopted so that policies and guidelines are developed promoting models of good practice and creating structures where these can be maintained.
- Further research into the needs and feelings of people with intellectual disabilities needs to be undertaken.

In terms of policy and organisational input, there is a need to develop clear policies and guidelines which are evidence-based to support staff and help build effective services. Alongside policy, staff development is essential. As well as a willingness on the part of staff to be involved in RSE delivery appropriate staff training is essential to the maintenance of good practice models, increasing confidence and competence levels and encouraging collaborative work practices.

1. Introduction

1.1 Research Background

Sex and sexuality are generally considered taboo subjects, with personal values and religious beliefs often overshadowing the need to provide accessible, accurate information (Irwin, 1993). Some argue that the unwillingness to discuss sexual matters is linked to a fear that discussion may encourage young people in particular to have sex (Cambridge 1996), even though there is no robust research evidence to suggest this is the case (Fullerton, 2005, Burtney *et al* Forthcoming). Relationships and sex education (RSE) was introduced to schools in Ireland in 1996. However, there are still few up-to-date guidelines on personal relationships and sexuality in an Irish context (Evans, 2002) to allow schools to take a supported and consistent approach to RSE delivery.

People with intellectual disabilities face greater barriers than the general population when it comes to accessing appropriate information and support. The accessibility and availability of RSE is influenced by broader societal discourses of people with intellectual disabilities which suggests they are viewed as perpetual children requiring protection from sexual knowledge, are not interested or not capable of sexual expression, or conversely as overly interested in sex and unable to control their sexual urges. As a result sexuality is either ignored or avoided and restrictions placed on the development of relationships and friendships (Cambridge, 1996).

Current thinking in the field of intellectual disabilities would challenge these myths and suggest that RSE is important in providing a mechanism through which individuals with an intellectual disability can have access to appropriate and accurate information, are recognised as sexual beings and are provided with a platform to address aspects of their sexuality, which has heretofore been unavailable to them. In addition, RSE can provide opportunities to develop appropriate sexual behaviour and reaffirm the message that their sexuality is respected (McCarthy and Thompson, 2001). While authors recognise the issue of protection as an important factor, it is argued that this

should be balanced alongside the right of people with intellectual disabilities to have support to express their sexuality rather than used as an excuse not to provide RSE.

While there has been a shift in the landscape and recognition from within the intellectual disability field that people with disabilities are entitled to sexual expression and sexual relationships, the thinking would appear to be ahead of practice and research (Burtney and Fullerton, 2006). Staff working with people with intellectual disabilities may defend the notion of sexual rights and RSE for people with intellectual disabilities, but their ability to provide support on the ground is hampered by organisational ethos to 'play it safe', the lack of training and confidence to provide RSE, and the impact of their own values and beliefs with regard to sexuality (Long, 1999).

In an attempt to understand further the current picture of RSE delivery in Ireland, this study aims to go some way in establishing the current provision of RSE in Ireland for people with intellectual disabilities and to describe the content of courses currently available and the delivery methods employed. To provide and sustain comprehensive RSE education involves amongst other factors, the appropriate training and support of staff delivering RSE. The study will also aim to identify the type and extent of training undertaken by those delivering RSE, highlight gaps in training available and provide an opportunity to establish training needs and concerns.

The study was commissioned by the Irish Sex Education Network, with funding from the National Disability Authority (NDA) and the Crisis Pregnancy Agency (CPA). The views and opinions contained in the report are those of the authors and do not necessarily reflect the views or opinions of the NDA or the CPA.

1.2 Research Aims

The project has three inter-related aims:

1. To examine international literature and draw together common themes and suggestions for quality programme delivery and staff training
2. To conduct research on the current status of relationships and sex education practice for people with an intellectual disability in Ireland
3. To make recommendations for future best practice

1.3 Desired Outcomes

The desired outcomes of this research are:

- To create an awareness of current RSE programmes available for people with an intellectual disability in Ireland;
- To increase knowledge of the professional and qualification profiles of individuals facilitating RSE for people with intellectual disability in Ireland, and the types and effective elements of the training received;
- To extend knowledge by making recommendations for models, strategies and guidelines for best practice; and
- To inform future research and development of RSE in the field of disability in Ireland

1.4 Scope and Limitations

The scope of the survey is nationwide and encompasses all intellectual disability agencies in all Health Service Executive Areas. The research element examines the extent of RSE delivery in the field of intellectual disability, and the training and qualifications of persons delivering RSE programmes. Staff attitudes to RSE delivery are further explored, as are their current perceived training needs.

1.5 Structure of the Report

The findings from the research are presented in the following chapters. Chapter 2 presents the findings from the literature review. Chapter 3 outlines the research methodology for the survey research before presenting the findings from the survey in Chapter 4. The report concludes with recommendations for future policy, practice and research.

2. Literature Review

2.1 Introduction

This chapter will draw on the current available national and international research evidence relating to RSE provision for people with an intellectual disability. The review is based on publications from Australia, the USA, Canada and Britain, and from this body of research draws examples of approaches to promoting sexual health for people with a learning disability and suggests recommendations for future delivery of RSE in Ireland. Research in the field of sexual health and intellectual disability is limited and the majority of studies stem from outside Ireland. Therefore the extent to which findings can be transferred to an Irish context should be kept in mind when reading the review.

The review commences with a historical overview of some of the issues contributing to the RSE debate and its development in relation to intellectual disability. Key themes emerging from international and national policy in relation to sexual health promotion among people with intellectual disabilities are outlined. Consideration is given to different approaches to RSE and goals, themes and content as suggested by the literature, before presenting a review of available evidence of the effectiveness of RSE programmes and staff training courses in promoting positive sexual health among people with intellectual disabilities. The chapter concludes by drawing together common themes and recommendations from the literature, which relate to and inform the current study.

2.2 Historical Perspective

Historically, the sexual health rights and needs of individuals with an intellectual disability have been denied. For example, the Eugenics Movement saw the introduction of enforced sterilisation legislation in 42 States in America between 1907 and 1948 which attempted to 'breed out' people with disabilities who were

characterised as sexually deviant (Wade, 2002). While the philosophy of the movement was challenged post World War 2, the legislation in the US on involuntary sterilisation was not changed until the 1970s (Griffiths and Lunsky, 2000).

Closer to Ireland, a key finding of the UK Royal Commission in 1904 was that “certain classes of ‘mental defectives’ should be segregated from the community and from each other in the interests of their protection and that of the community” (Wheeler 2003: 22). This Commission influenced the development of the 1913 Mental Deficiency Act which had a lasting influence on how people with intellectual disabilities were viewed by society.

The separation of people with intellectual disabilities from society in residential settings continued until the philosophy of normalisation was described by Nirje in 1976. This began a process of change in attitudes toward people with intellectual disabilities which led to their de-institutionalisation and integration into mainstream society and began to afford improved access to general rights and services.

However, despite these transformations and the increasing focus on sexual health policy more generally during the 70s, people with intellectual disabilities were not afforded the same rights as the general population and limited change was noted in addressing their relationship and sexuality needs (Whitehouse and McCabe, 1997). Policy tended to be influenced by the views that people with intellectual disabilities were asexual, forever childlike, and vulnerable. This resulted in an emphasis on protection rather than sexual rights. Additionally, segregation from society meant people with intellectual disabilities had little opportunity to develop relationship skills (Davis 2000). Much of the expert opinion at the time focused on issues of abuse and ability to consent, which are important but distracted policy from addressing sexual health needs (Cambridge and MacCarthy, 1997; Wade, 2002, Wheeler, 2003). Writers in the area have expressed concern over the protection model as it could be viewed as a front for an inability to accept the fact that people with intellectual disabilities have sexual rights (Brown, 1994).

It is only recently that there have been noted changes within policy, with debate focusing on sexual rights and needs of people with intellectual disabilities. Writers in the field such as Hilary Brown in the UK, and David Hingsburger in Canada have helped move the debate from protection and consent issues to sexual rights and expression.

The European Convention on Human Rights openly supported the rights of people with intellectual disabilities to explore and express their sexuality and have positive relationships. Since then, some organisations have chosen to introduce the sexual health needs of people with intellectual disabilities into learning disability policy and reviews. For example, in Scotland *The Same As You?* report (Scottish Executive, 2000) reviewed services for people with intellectual disabilities and stated:

‘professionals and services need to recognise that adolescents and adults with learning disabilities have sexual rights and needs, while at the same time making sure those who may be vulnerable to abuse are protected’
(2000:94).

Additionally, some countries have included specific references to meeting the needs of people with intellectual disabilities within sexual health policy and guidelines. For example in Northern Ireland *Myths and Realities* the teenage pregnancy strategy (DHSSPS, 2002) makes a number of references to the needs and rights of young people with intellectual disabilities, and the recently drafted sexual health strategy *A Five Year Sexual Health Promotion Strategy and Action Plan* consultation document identified priority groups which included people with disabilities who require specific attention in relation to full and adequate access to sexual health information.

“Those with a disability or from a black and minority ethnic community have particular requirements in accessing information, advice and services and these must also be addressed (p:15).

Across the UK, this focus on sexual health and intellectual disability at national levels has begun to filter down to local areas and organisations and a number of sexual health and learning disability policies are available. For example, in Scotland the Lothian Health Board *Making Choices Keeping Safe* policy (Lothian 2004) is specially focused on meeting the sexual health needs of people with intellectual disability. In Northern Ireland local health and social services trusts have developed specific policies in regard to sexual health and intellectual disabilities e.g., Foyle H&SS Trust and Sperrin Lakeland Trust 2000.

2.3 Current assessment of sexual knowledge and experience of people with intellectual disabilities

Little research has been conducted in Ireland or the UK with regard to levels of sexual health knowledge, experience or activities of people with intellectual disabilities. However, when considering RSE programmes for people with intellectual disabilities, it is important to establish a baseline in order to develop appropriate and useful programmes. In Northern Ireland, researchers from the University of Ulster in partnership with the fpaNI are currently completing the SKY project, a three year study exploring the sexual health needs of adults with learning disability (Audrey Simpson & Roy Mc Conkey, Personal Communication April 2006). In addition, Population Health within the Health Service Executive has recently commissioned a similar research project in the Republic of Ireland.

International research evidence would suggest that people with intellectual disabilities have poor sexual health knowledge (Cheng and Udry, 2003; Galea et al., 2004; Lesseliers and Van Hove, 2002; Szollas and McCabe 1995). In a specific study of risk for HIV, McGillivray (1999) found significant differences between levels of learning in the intellectually disabled adults and non-intellectually disabled adults in relation to HIV and condoms and adults with ID were less skilled in assessing risk situations. Relationship and Sexuality Education for people with intellectual disabilities is important to bridge this gap. Szollas and McCabe (1995) concluded:

'it would seem that the information and skills which people with intellectual disabilities require to live in the community have not kept pace with the changing societal attitudes embodied in deinstitutionalisation'

(Szollas and McCabe 1995: p216).

Major gaps have been identified in people with learning disabilities' knowledge of safer sex messages and in their safer sex practices. For example, McCabe (1999) examined the sexual knowledge, experiences, needs and feelings amongst a sample of 60 people with learning disabilities, 60 disabled people and 100 people from the general population. The research found that levels of knowledge about sexual health issues was lower for people with learning disabilities than for people with physical disabilities, which were in turn, lower than for the general population. It was found that information and education in areas of sexuality in the general population were drawn from parents and friends as well as formal education. The study concluded that

'...disabled respondents have a strong need to experience dating, intimacy and sexual interaction, but due to lack of knowledge, their negative feelings about sexuality and perhaps their lack of opportunity for sexual expression, they are currently unable to engage in these experiences'

(McCabe, 1999, p.168).

The lack of information is linked to the limited opportunities that people with intellectual disabilities have to learn about sex. Recent research from England would suggest that there is a lack of available and appropriate sex and relationship education (Bucknall, 2005) and an over-reliance on parents for information (Bucknall, 2005; Grant and Fletcher-Brown 2004). This is problematic as many parents face barriers when thinking about RSE for their child, regardless of the age of the child. Barriers parents face relate to fears, in particular of the safety and vulnerability of their

child, their own lack of knowledge and the fear that discussion will encourage sexual activity (Grant and Fletcher-Brown 2004). In addition, some parents live in denial of their child's sexuality and so don't see the need to provide RSE (Swain and Thirlaway 1996).

In addition to a lack of sexual knowledge, the limited research available would indicate people with intellectual disabilities hold negative attitudes toward sex and sexuality. In part this is linked to the views of others and an understanding that others would disapprove of their sexual activity (Johnson et al 2002) and their fear of the consequences of being found out (Craik 2002; Lesseliers 1999).

An important barrier faced by people with intellectual disabilities in the formation of relationships is the attitudes of people they live with and the attitudes of staff that support them (Abbott & Howarth 2005). In providing people with a 'protected' environment, many parents/carers deny them access to opportunities to form relationships.

Research by McCarthy and Thompson (1994) based on interviews with 220 people with intellectual disabilities found that many people with intellectual disabilities experience a lack of privacy for sex. The research found that sexual activity between men occurs with a similar frequency as sex between men and women (lesbian sex was found to be extremely rare), and that power imbalances existed in sexual relationships between men often due to differences in intellectual ability (in many cases men disclosed regularly having sex with strangers in public places).

Nonetheless, people with intellectual disabilities report sexual intimacy and sexual activity (Lesseliers, 1999; Konstantareas and Lunsky 1997; Lesseliers and Van Hove) but have less experience than non-intellectually disabled peers (McGillivray, 1999). Lower levels of sexual activity can be linked to lack of privacy and difficulties in developing and maintaining satisfactory peer and sexual relationships (Szollas and McCabe, 1995).

People with learning disabilities often face prejudice and harassment in their daily lives (Mencap, 1999 cited in Abbott & Howarth 2005). Many of these experiences of prejudice are also shared by the Lesbian, Gay & Bisexual (LGB) communities. Lesbian and gay people with intellectual disabilities who are trying to make choices about their sexual identities may face additional discrimination and opposition (Abbott & Howarth, 2005). People with intellectual disabilities who identify as gay are more likely to experience social isolation than their non-disabled peers, can be further isolated by their experience of exclusion and lack of support from other people with intellectual disabilities and may face additional prejudice from other LGB people.

Whilst there is some information available on the sexual behaviour of people with intellectual disabilities, there is little or no information available on the sexual health or ill-health of people with intellectual disabilities. Statistics on HIV/AIDS and sexually transmitted infections fail to record information on the intellectual status of those infected. However, needs assessment work across the UK confirms a high level of sexual risk behaviours for men who have sex with men with learning disabilities (Cambridge 1994, McCarthy 1994, Withers et al 2001). No equivalent research is available for the Irish context.

2.4 Promoting Sexual Health of People with Learning Disabilities

It is evident from a review of international research evidence that people with intellectual disabilities have a need for information and education about relationships and sexuality. How and when this information / knowledge is provided is less clear. A recent review of the international research literature on sexual health promotion with young people with learning disabilities outlined four possible sexual health promotion strategies which include the provision of Relationship and Sexuality Education, training and support programmes for parents / carers, training and support programmes for professionals and agencies working with young people with learning disabilities and improved access to sexual health services (Burtney et al. Forthcoming). These are summarised in Box 1 below.

Box 1: Sexual Health Promotion Strategies and Approaches

Possible approaches to the delivery of sexuality and relationship education (SRE) for young people with intellectual disabilities

- Home based SRE
- School based SRE
- Community based SRE
- Peer based SRE (community or school)
- Self-help and support groups (Advocacy or befriender groups)

Possible approaches to supporting parents / carers promote sexual health among young people with intellectual disabilities

- One-off workshops for parents
- Intensive support programmes for parents
- School based programmes which involve parents (e.g. through courses to describe the programme or through homework assignments)
- Development and dissemination of printed materials resources for parents

Possible approaches to supporting professionals / carers promote sexual health among young people with intellectual disabilities

- Policy development and implementation
- Training and support (including mentoring)
- Development and dissemination of printed materials/resource packs

Possible approaches to promoting access to sexual health services for people with intellectual disabilities

- Specialised or tailored services for people with intellectual disabilities
- Visits to sexual health services to introduce the person with intellectual disabilities to the service and to explain the services provided
- Provision of a link worker to accompany the person with intellectual disabilities

Source: Burtney et al Forthcoming

It is important to consider each of the four strategies described by Burtney and colleagues when planning sexual health promotion programmes to ensure that the specific and broad needs of all relevant groups are considered and to view each strategy as playing an important contributory role to the overall success of the

programme. However, for the purpose of this research, the main focus is on the provision of RSE for people with intellectual disabilities which is achieved through the direct delivery of RSE and the support and training for parents and professionals to deliver RSE.

2.4.1 Relationship and Sexuality Education

It is evident from the research literature that there is an emerging consensus that RSE plays an important role in the promotion of positive sexual health of all young people, including those with disabilities, and that people with intellectual disabilities have a right to access Relationship and Sexuality Education (Whitehouse and McCabe, 1997). Relationship and Sexuality Education is lifelong learning about physical, moral and emotional development and sexual health issues. It provides information and skills about sex, sexuality and sexual health. It can happen in a variety of contexts, within groups or on a one to one basis. It is not confined to schools but is the responsibility of families and the wider community, and continues throughout life (Hasler, Yates and Anderson, 2005).

If RSE is to assist people to understand that their sexuality can be a positive force it is important that both policy makers and practitioners have prior information about the knowledge, attitudes and experience of persons with intellectual disability so that appropriate goals can be set and the delivery of programmes measured against these goals (McCabe & Schreck, 1992). If this information is not available then it is difficult to ascertain where the deficits lie and what areas need addressing in training.

“We need to determine the current knowledge and experience base of people with intellectual disabilities, develop appropriate training programmes for these people and their caregivers and finally allocate sufficient resources so that these training programmes can be implemented.” (McCabe & Schreck, 1992).

Griffiths (1999) noted, from a Canadian perspective, that most learners with an intellectual disability receive sexuality education only after an episode of offensive, dangerous or otherwise socially inappropriate sexual behaviour.

Griffiths outlined the basic goals for RSE instruction as to:

- Include the provision of direct and accurate information
- Assist the learner in the development of a system of personal values regarding sexual expression
- Develop social competence to engage in appropriate sexual behaviour
- Combine with the provision of comprehensive sexuality instruction and the education of society at large, the promotion of research into which systems, curricula, methods or strategies are most likely to result in outcomes that support a safe and positive quality of life.

More recently, Grigg (2001) constructed a set of goals of sexuality education for people with intellectual disabilities which are summarised in Box 2 below. She highlighted that the above goals may not be achievable with people with profound or severe intellectual disabilities but stressed that it is important that those caring for people with profound or severe intellectual disabilities are sensitive to their sexual needs, and argued that any sex education programme can be modified to suit the capacity and comprehension of people who might have more difficulty in grasping concepts. It is important to note that different approaches and methodologies may be required to meet the different abilities of people with intellectual disabilities.

Box 2 Goals of sexuality education for people with intellectual disabilities

- To give accurate information
- To teach people about their bodies in order to enhance self-confidence and self-esteem
- To educate people to avoid situations in which they could be sexually exploited
- To prevent people from becoming involved in inappropriate sexual behaviour that will make them socially unacceptable or get them into trouble with the police
- To enrich people's lives by acquiring social skills to help them to enjoy the company of others
- To help prevent over-protection that arises from others' fear of procreation by offering information and help with contraception
- To help people understand the responsibilities of being a sexual person through appropriate sexual behaviour and customary social patterns of behaviour
- To help people achieve some insight into the commitments of having a permanent partner, getting married and parenthood so that they might have realistic goals for their future
- To help people communicate about sexuality without unnecessary guilt or embarrassment

Source: Griggs (2001) cited in Burtney *et al.* (*Forthcoming*)

Hingsburger (1987) suggested a number of issues for consideration in the development of programmes:

- Establishment of skills to form relationships with peers

- Provision of sexual knowledge
- Development of a positive attitude towards sexual behaviour
- Development of positive self esteem
- Attention to resolving feelings associated with previous negative sexual experiences
- Acceptance of the sexual behaviours and beliefs of peers
- Designing programmes to address individual needs and learning abilities
- Changing attitudes as well as providing information
- Involving parents or caregivers as appropriate

The suggestions above should be underpinned by an assessment of the learner's current knowledge and attitudes prior to attending a programme.

An Australian study (McCabe 1999) explored the sexual knowledge, experience, feelings and needs of people with intellectual disability or physical disability and compared their needs and experiences to the general population. The research involved 60 adults with a mild intellectual disability, sixty adults with a physical disability and one hundred adults from the general population. McCabe found that only 50% of respondents with a disability had received some form of sex education, compared to over 80% of the general population. The study found that even where sexual health education had been provided, greater effort was required to improve the sexual knowledge of people with disabilities. Among respondents without a disability the main source of sex education was most likely to come from parents, family and friends. Respondents with a disability were most likely to receive their sex information from 'other' sources such as the media and formal sex education classes only. This suggests that there is less discussion of sexual issues with family and friends amongst the disabled respondents, which may in turn convey negative messages to those with

a disability about their own sexuality. The low levels of knowledge amongst those with a disability may suggest that formal education alone is ineffective and not meeting their needs. McCabe contended that it is not sufficient that people receive information alone on sexual issues and suggested that:

- Information needs to bring about changes in knowledge both in the short and long term so that it improves their experiences of personal and sexual interactions.
- Sexuality needs to be normalised among people with a disability and must include the freedom to discuss sexual matters with family and friends so that their sexuality becomes more integrated into their lives.
- There is a need to evaluate sex education programmes by determining the change in sexual knowledge and feelings about sexuality after completing a training programme.

Davies (2000) introduced a radical user-led empowerment project on sex and relationships for people with disabilities. As highlighted in the previous section, early work on sexuality and disability concentrated on such themes as the prevention of sexual abuse or inappropriate sexual expression. The approach suggested by Davies aims to focus on developing self image and confidence, enabling the development of self-actualisation through peer-led training and education, supported by what he calls “trained allies”. At a very basic level he suggested the inclusion of communication skills, assertiveness training, listening skills and the enhancement of self-esteem. Davies recommended that such courses be developed as certificated courses and ideally validated by a university and run on a modular basis.

Sexuality training programmes, which include an emphasis on social relationships and self esteem are now delivered in the US, Australia, Britain and other European countries. (Section 2.8 presents a summary of the current evidence of the effectiveness of such approaches).

2.5 Curriculum considerations

Kupper (2000) examined the need for sexuality education for young people with disabilities in the US and suggested a number of issues for inclusion in RSE programmes. The materials should reflect and be specifically designed for people with intellectual disabilities and should also be adaptable to many different abilities and disabilities. Ideally programmes should be tailored to the age and ability level of the learner and RSE education must be an ongoing process over many years to fully realize maximum benefit rather than one-off sessions.

Over a decade ago, Irwin (1993) outlined a number of areas for consideration when developing Relationship and Sexuality Education programmes. Information is needed in a number of health related areas throughout life and whilst generic education materials may be appropriate in most cases of disability, some may need to be modified. People with cognitive impairment may, for example, require materials that are presented with pictures, photographs and possibly modified vocabulary. People with additional physical and / or sensory disabilities may also have information and training needs, which relate to sexual functioning, particularly if faced with mobility limitations or when easily fatigued. Clear teaching and instruction relating to boundaries, privacy, acceptable and unacceptable behaviours, touch, etc., is necessary to avoid possible abuse.

Kempton and Kahn (1991) recommended that general sexual health education curricula include more than the basic information on contraception and the mechanics of sex and also include topics which cover body image and communication skills etc, which bring about greater knowledge and behavioural change in both the short and long term. The benefits of increased social skills and assertiveness levels through RSE delivery have demonstrated greater independence as well as a reduced risk of sexually transmitted infections and crisis pregnancies amongst individuals with an intellectual disability (Disability Online, 2003).

2.6 Staff / Carer training considerations

Cambridge (1996) contends that even with increased availability of sexuality training and education, reluctance remains on the part of society in general to talk about sex. This general reluctance may have an impact on professional staff working in the area of intellectual disability who may be embarrassed to discuss sexuality issues with clients.

Research with staff would indicate that general attitudes towards sexuality are more liberal nowadays compared with the late 70s and early 80s (Murray and Minnes, 1994; Griffiths and Lunskey, 2000). More liberal is taken to mean 'ability and willingness of staff to support clients to make informed choices about sexual expression and put them into practice' (Murray et al., 2001: 30).

A study of staff attitudes to sexuality and people with intellectual disabilities in Northern Ireland reported by Ryan and McConkey (2000) found that attitudes have become more liberal than noted in previous studies. Staff were well disposed to their service users receiving sex education and supported marriage and the need for privacy around sexual behaviours including masturbation. However, attitudes to homosexuality and service users having one-night-stands were more conservative.

More positive attitudes are linked to younger staff members (Cuskelly and Bryde, 2004; Murray, et al. 1995; Plaute et al, 2002), staff with higher levels of education attainment (MacDonald et al. 1999; Murray and Minnes 1994) and non direct care staff (MacDonald et al 1999; Murray and Minnes 1994).

However, despite these positive attitudes towards the sexuality of people with intellectual disabilities, staff attitudes may be tempered by the organisation ethos, which can often be a 'play it safe' attitude, where opportunities for sexual encounters are limited through lack of privacy and lack of opportunity to meet people and explore sexuality (Finnegan and Clarke, 2005) or sexual encounters are discouraged as they inconvenience the staff (Paul et al., 2004).

In addition to organisational barriers, staff identify a number of other barriers to the delivery of RSE including, a lack of confidence (Christian, et al., 2001; Evans 2002), a lack of training (Christian, et al., 2001; McConkey and Ryan, 2001), concern over parental reactions (Swain and Thirlaway, 1996; Wheatley, 2005) and the lack of clear policy guidance (McConkey and Ryan 2001).

In one study in Ireland, Evans (2002) found that one in five (20%) of Galway Association staff lacked confidence in their ability to discuss sexuality issues and nearly all (95%) staff stated that they would be interested in receiving training. Similar findings were reported by Allen (2004), who researched service users, staff and carers from NTDI, Abode and Enable Ireland and found that two thirds (62%) of respondents amongst both staff and carers had discussed sexual health issues. However, issues mainly concerned pregnancy and menstruation. Staff described low confidence levels in relation to discussing sexual matters and all three groups expressed a strong desire to avail of training to support the delivery of RSE for people with intellectual disability.

An Australian model for staff working with people with a disability in the area of RSE is outlined by Chivers & Mathieson (2000). They found that although staff had undertaken in-service training on disability and sexuality, they remained reluctant to undertake this training themselves and continued to use outside 'experts' to address such training provision with service users. They suggest that the dominant 'discourse' within the organisation in relation to RSE was biological. Typical course content had included sexually transmitted infections, pregnancy and contraception with an implied emphasis on danger and risk. Such an emphasis separates sex from intimacy and reinforces isolation for people with disabilities. Furthermore, it suggests an attitude that emphasises the physical nature of sex. If service users are not engaging in penetrative sex, then they are seen to have no sexual needs. Thus learning goals such as exploring their own sexuality, developing friendships and the need for intimacy, are not considered.

In examining staff feelings on why they see 'experts' as appropriate to deliver sexuality training, they found difficulties in attempting to define competency standards for such trainers and as a result consulted independent trainers and practitioners who characterised their own work as, requiring self awareness, the need to be the "right kind of person", that not everyone can work in this area and that it's not possible to write competencies for this type of work. Chivers & Mathieson suggest that such comments support the notion that in order to undertake such training one needs to have the 'right' attitudes and values. Thus, sexuality is separate and as such limits general staff from providing support because they feel it requires particular self knowledge that they cannot have making it a more difficult area to work in, requiring specialist skills.

"The expert model serves to prevent staff from working collaboratively with individuals with a disability to identify and meet their needs and desires. It also serves to restrain staff from creating meaningful working partnerships" (Chivers & Mathieson, 2000, p.77).

In developing the staff training programme, participants were encouraged to direct their own learning rather than being passive recipients of 'correct' information and attitudes. Participants were encouraged to critically examine dominant discourses thus empowering and supporting staff to make choices about how they work. Addressing the less dominant areas of desire and intimacy were focused upon in the training, as was an examination of alternatives to expert or professional roles.

Staff training was delivered both in and outside of their work situation and staff were accredited within the organisation to train the programme, thus embedding the training into the culture of the organisation. Strong links were also made with policy and training departments of the organisation by including key policy makers in the process, which served to add to the collective consciousness.

Other studies, as indicated in the Chivers & Mathieson (2000) Australian study above, have shown that staff who had undertaken training were more disposed to supporting expressions of sexuality amongst service users. Staff training should therefore be a primary consideration. Training should focus on all aspects of sexuality, including attitudes, values and beliefs and they suggest that having mixed gender staff training groups might allow for a wider range of opinions to be addressed. Staff should be assisted to distinguish between their own personal values and those of others and organisational policies should underpin methodologies (Ryan and McConkey, 2001).

In the University of Ulster, Prof Roy McConkey has developed an Introduction to Relationships and Sexuality as an e-learning module through the University of Ulster. The course addresses issues affecting service staff in relation to relationships and sexuality in the workplace. The course is divided into six units and covers Human Sexuality and Intimate Relationships, Nurturing Relationships, Working in Partnerships, Legal Issues, Responding to Situations and Imparting Knowledge.

2.7 Organisational / Policy issues

Organisations and institutions also have concerns around the legal implications of RSE delivery which may be linked to a lack of understanding. A study of Galway Association staff by Evans (2002), demonstrated that only a minority were aware of the legal position in terms of the types of relationships permitted for service users and some staff raised legal issues as something they were not confident about.

To clarify, the current law on the age of consent for sexual relationships is under review. However, whatever the legal age of consent, there are issues as to whether people with intellectual disabilities have a legal capacity to consent to sexual relationships. Section 5 of the Criminal Law (Sexual Offences) Act 1993 states that it is an offence to have or attempt to have sexual intercourse or to commit or attempt to commit an act of buggery with a person who is “*mentally impaired*”.

“The criminal law aims to protect people with intellectual disabilities from sexual exploitation but it can be argued that it goes too far and prevents people from having appropriate and satisfying relationships. In many cases, it reduces people’s ability to make personal decisions and as a result, reduces their ability to live independent, autonomous lives and removes their right to sexual fulfilment” (NAMHI 2003)

The current legislation defines “mentally impaired” as “being incapable of living an independent life. But many people with intellectual disabilities are incapable of leading independent lives, although capable of protecting themselves against exploitation. The criterion of being incapable of guarding against serious exploitation is a more appropriate definition and it requires an individual assessment (NAMHI, 2003).

Furthermore, there is currently no legal mechanism in Ireland for supported decision-making, placing service providers in a vulnerable position when attempting to develop policies (Brown, 2003). Additionally, there is no national guidance or policy available for organisations to direct and support organisational responses to supporting the sexual rights of people with intellectual disabilities.

Therefore organisations are often fearful of the consequences of developing policies, both in terms of interpreting the legal aspects but also the linked resources in terms of sexuality training, support services and access to privacy, which have personnel and funding implications. However, to actively support people with learning difficulties, policies and guidelines need to be developed into individual and service level contracts, which protect rights and prevent individuals being subjected to the whims of individual staff or institutions (Brown, 1994), and which support staff and provide clear guidance on their role (Grant and Fletcher-Brown 2004).

However, it is not enough to write a policy, as often this does not ensure staff knowledge (MacDonald, 1999; McConkey and Ryan, 2001), understanding or adherence to the policy (Christian, et al., 2001; MacDonald, 1999). It is important to

support policy implementation through training, ongoing review of policy and supervision.

In addition to policy, service options need to include greater living options than are currently available. Services still operate under the notion that individuals with intellectual disabilities are going to lead asexual lives so there is little support for providing private space, or assistance for people to live together.

2.8 What Works? Evaluated RSE programmes for people with intellectual disability

The evidence presented in this section is predominantly based on two reviews of the research evidence on the effectiveness of sex education (Whitehouse and McCabe 1997) and sexual health and wellbeing work with people with intellectual disabilities (Burtney et al Forthcoming). The first of these reviews (Whitehouse and McCabe 1997) had a focus on sex education programmes which have been developed for people with intellectual disabilities. The second review (Burtney et al, Forthcoming) was recently commissioned by Health Scotland, and has a focus on the effectiveness of sexual health and wellbeing work directed to young people with learning disabilities.

A large number of relationship and sex education programmes for persons with intellectual disability have been developed over the past twenty years, ranging from broad based programmes to programmes designed to address specific areas of concern such as protection from abuse. However, most programmes have focused on the transmission of knowledge and not on the development of positive attitudes to sexuality (Whitehouse & McCabe, 1997). Furthermore, Whitehouse and McCabe state that:

“...most of the sex education programmes are developed from the perspective of professionals and their beliefs about

what is necessary information for people with intellectual disability” (p231).

In their review of sex education programmes for people with intellectual disabilities, Whitehouse and McCabe (1997) considered the available research evidence for a range of RSE programmes developed during the eighties and nineties. They grouped such programmes into five categories (1) sex education programmes, (2) broad spectrum sex education programmes, (3) social skills and relationship programmes, (4) reproductive health programmes, (5) protective behaviour programmes, (6) HIV/AIDS programmes, and (7) programmes designed to enhance positive attitudes to sexuality. Table 2a below presents a short summary of the included evaluation studies cited in the Whitehouse and McCabe report.

Table 2a Summary of evaluation studies of different approaches to SRE

Study	Category/Approach Target group	Evaluation design Outcome measure	Findings	Commentary
Bennett et al (1972) Reviewed by Whitehouse and McCabe (1997)	Sex education Young women with intellectual disability	Before and after study Knowledge No details on follow-up period No details on numbers of participants	Authors report some increases but no data presented	Weak design (no control group) Authors note that those who had some knowledge benefited more than those with little.

Study	Category/Approach Target group	Evaluation design Outcome measure	Findings	Commentary
Penny and Chataway (1982) Reviewed by Whitehouse and McCabe (1997)	Broad Spectrum Sex Education Programme Adults with mild to moderate intellectual disability 6 sessions	Before and after study Knowledge (Sexual Vocabulary Test) No details on follow-up period No details on numbers of participants	Authors report increases in sexual vocabulary.	Weak design (no control group)
Robinson (1984) Reviewed by Whitehouse and McCabe (1997)	Broad Spectrum Sex Education Programme No details provided in review	No details provided in review Sexual attitudes and attitudes using SSKAT	The authors report increased positive attitudes but no statistical analysis completed	Not enough information provided on the design of the study
Lindsay et al (1992)	Broad Spectrum Sex Education Programme	Experimental design (Control and comparison group before and after) Sexual knowledge	At 3 month following the experimental group had higher knowledge levels than control	Not enough information provided on the content of the programme in the review

Study	Category/Approach Target group	Evaluation design Outcome measure	Findings	Commentary
Jupp & Looser (1988)	Social skills and relationship programmes CATCH programme	No details provided in the Whitehouse and McCabe review	Evaluators reported improvements in a limited number of social skills but these skills tend not to generalise to situations not encountered during training	Not enough detail provided on the design of the evaluation.
Valenti-Hein, Yarnold and Mueser (1994)	Social skills and relationship programmes No name of programme	No details provided in the Whitehouse and McCabe review	Evaluators reported improvements in social skills but participants' levels of anxiety in social situations remained	Not enough detail provided on the design of the evaluation.
Bauman & Bailey (1984)	Reproductive Health Programmes	No details on the evaluation design provided by Whitehouse and McCabe review	Improved behavioural skills	Not enough detail provided on the design of the evaluation.

The following sections provide a brief description of Whitehouse and McCabe's seven categories of approaches to sex education and outline the available evidence of the effectiveness of these approaches (1997).

- **Early Sex Education Programmes** were designed to cover a range of topics relating to sexuality and were usually run in groups. Whitehouse and McCabe (1997) provided an overview of the findings from evaluations of sex education programmes. The earliest of the studies was undertaken by Bennett, Vockell & Vockell (1972) who were the first researchers to evaluate a sex education programme for young women with intellectual disability. The programme covered topics such as menstruation, puberty, sexual feelings, and interactions. The study employed before and after measures using the Sex information Inventory for Girls to evaluate the effectiveness of the programme. While no quantitative data were presented in the study, the authors reported that the young women showed an increase in their knowledge of the topics covered in the programme. However, the absence of a control group and the limited information on follow-up period weakens the strength of the study.
- **Broad Spectrum Programmes** were designed to cover a broad range of topics regarding sexuality and were usually run in groups. However, Whitehouse and McCabe (1997) found that many of such programmes either failed to evaluate their programmes or when they did do so, used inadequate measures or comparison groups. One Australian programme reviewed by Whitehouse and McCabe that provided evaluative data was reported by Penny and Chataway in 1982. The programme which covered male and female body parts, reproduction, sexual interactions, contraception and sexually transmitted infections was delivered to adults with mild to moderate intellectual disability and provided over six sessions. Using a sexual vocabulary test, participants were tested both before and after the programme. The programme was found to increase the sexual vocabulary of participants and their sexual knowledge from one post-test measure to the next. No measures were employed to

ascertain if participants were able to make conceptual links between the topics to indicate a broader understanding of the issues and no measures were used to assess whether participants had developed more positive attitudes towards sexuality. Furthermore, the absence of a control group makes it difficult to judge the overall effectiveness of the programme.

The Whitehouse and McCabe review included a UK study by Lindsay et al (1992) which examined the sexual knowledge of a group of adults with intellectual disabilities after completion of a sex education programme. It is not clear from the review who participated in the study. Both the study group and the control group were assessed for sexual knowledge before and after the programme completion using a questionnaire covering body parts, masturbation, puberty, intercourse, pregnancy and sexually transmitted diseases. Before the programme there were no significant differences between the two groups on the level of sexual knowledge. However, three months after the programme the study group had significantly higher levels of knowledge than the control group. Whitehouse and McCabe suggest this to be one of the few studies to provide adequate pre-and-post test measures, use of control group and evaluative data on information retained by participants. They note, however, that the study did not examine whether knowledge gained was transferable to participants' social interactions outside of the learning environment.

Although broad spectrum RSE programmes are widely implemented, the evaluations of such approaches are limited by a number of methodological flaws which weaken the strength of the evidence on their effectiveness. Many such evaluations fail to employ appropriate control measures and/or use inadequate measures to judge the programmes. Where programmes are evaluated the emphasis tends to focus on changes in sexual knowledge and include topics such as menstruation, puberty and sexually transmitted diseases rather than any changes in attitude or behaviour occurring as a result of a programme (Bennett, 1972). Whitehouse and McCabe argued that programmes which focus on increasing sexual knowledge without

increasing the positive attitudes of people with intellectual disability, ensure that people have information but not the permission to use the information.

- The third category described by Whitehouse and McCabe (1997) was **Social Skills and Relationships Programmes**. Social skills and relationships programmes focus on teaching people with intellectual disabilities about different types of relationships as well as appropriate behaviours within such relationships and in various social situations. Other goals of social skills and relationship programmes included teaching people with intellectual disabilities how to behave in social situations. In their review Whitehouse and McCabe described two educational resources which have been used in social skills and relationship training. The Circles Concept (Walker-Hirsch & Champagne, 1991) which uses coloured circles as a visual aid to learn about different relationships. The programme was designed to assist learners to act on knowledge gained, improve self-esteem, personal autonomy and use of protective behaviours. Despite being used widely, the Circles programme has not been adequately evaluated (Whitehouse & McCabe, 1996).

The second educational resource for social skills programmes described by Whitehouse and McCabe was the Australian-developed 'CATCH' programme (Sheppard, 1983) which was designed to teach learners eleven social skills including listening skills, eye contact and social distance. Evaluation of this programme by Jupp and Looser (1988) suggested limitations in transferring this learning to situations outside the training environment. In order for social skills programmes to be beneficial, they need to discover methodologies, which help learners increase their self-confidence and their skills and ability to relate to others.

- **Reproductive Health Programmes** educate about specific topics such as menstruation. The goals of these programmes have been to teach knowledge about and to increase behavioural skills in relation to menstrual management,

and have used behavioural measures. Use of such evaluative methods show the programmes have been successful in increasing behavioural skills, particularly in relation to menstrual management, but these programmes are only targeted at single issues (Whitehouse & McCabe, 1996).

- **Protective Behaviour Programmes**, A number of programmes have been developed specifically aimed at teaching learners how to avoid sexual abuse (Kempton, 1987, Walker-Hirsch & Champagne, 1986). Such programmes have a focus on the identification of appropriate and inappropriate behaviours such as touch that is OK and not OK, and on strategies to avoid abuse. However, many of these programmes have not been subjected to evaluation and as such their efficacy is difficult to measure.
- Some sex education programmes have a **single topic** courses such as specific programmes with a focus on HIV/AIDS Programmes. McCarthy & Thompson (1994) highlight the need for appropriate evaluation of such programmes. It cannot be assumed that giving factual information about risk taking is enough to guarantee behavioural change, particularly with people with intellectual disability. Studies of mainstream HIV prevention programmes also support this contention and indicate that knowing the risks does not necessarily translate into adoption of safer sex practice. Garwick & Jurkowski (1992) recommend that a Knowledge, Attitudes and Behaviour (KAB) model be adopted by educators to evaluate effectiveness of their interventions. Whitehouse and McCabe argue that while the KAB model would provide educators with a much clearer sense of effectiveness of their programme, the difficulty is obtaining a behavioural measure. Knowledge gained is easily measurable. However, the behavioural change element of the model remains problematic as it relies on the biased nature of self-report measures (Whitehouse & McCabe, 1997).
- **Positive Attitudes Models** concentrate on developing more positive attitudes to sexuality. Methods such as role play and facilitated negotiation games, in

which group members negotiate with one another about a particular issue with feedback from the interaction have been used to enhance positive attitudes of people toward sexuality. There is however, little research evidence of the effectiveness of such approaches. Lawrence and Swain (1993) developed a method of evaluation based on transcripts of sex education sessions to ascertain whether the goals of a positive attitudes model approach were reached. However, as no pre-programme measures were taken and no control group was included in the evaluation, it is difficult to conclude whether the programme had any impact on the participants in terms of their knowledge or feelings.

When considering all the available evidence on the effectiveness of sex education programmes for people with intellectual disabilities, Whitehouse and McCabe (1997) concluded that while there is a clear need for sex education for this population group, much of the available evidence on the effectiveness has a number of methodological flaws. A finding echoed by the recently completed review of the effectiveness of sexual health and wellbeing work with young people with intellectual disabilities (Burtney et al, Forthcoming) which found only seven studies evaluating sexual health and wellbeing work aimed at young people with intellectual disabilities. Of these seven studies, only three were assessed as being of excellent or adequate quality. Methodological weaknesses of the evaluative researching included the absence of control or comparison groups, small sample sizes, short follow-up periods, and limited outcome measures and data collection tools. The section below presents the evidence of short summary of the available evidence as presented by Burtney and colleagues (Forthcoming).

- Burtney et al located four studies which reported evaluations examining the impact of **school-based programmes**, three of which were assessed as being seriously flawed. The one study (Scotti et al., 1997) which was assessed as providing adequate level evidence (i.e., with some methodological flaws) had

a limited focus on HIV prevention but also included a skills based approach. The evaluation design lacked a control group. Follow-up of participants found significant increases in knowledge, some skills and behaviour (i.e. condom usage). In summary, this review of school based programmes aimed at improving sexual health and wellbeing among young people with intellectual disabilities has found some limited evidence of the effectiveness of school-based HIV focused programmes delivered to young people with intellectual disabilities (Scotti et al., 1997*).

- Burtney et al found that the available evidence base of the effectiveness of working with **parents** of people with intellectual disabilities is somewhat stronger than school-based work due to the existence of a US based randomised controlled study of a five week group based programme for parents (Ballan, 2002). Ballan's study provides an example of a well designed and conducted, evaluative project which benefited from extensive pilot work and qualitative work with parents in the development of the programme. While attempts have been made within the UK to evaluate programmes for parents, such programmes have relied on qualitative methods rather than the combination of both quantitative and qualitative methods (Blakely, 1996).
- Within practice there are a number of examples of training and support programmes for **professionals** (Burtney and Fullerton, 2006). However, Burtney et al found that the evidence base of the effectiveness of such programmes in changing professional practice has not been well developed. This review identified one adequate level study with a focus on professionals (Plunkett et al., 2002). Similarly, while there are a number of practice examples of improved **sexual health service provision** for people with intellectual disabilities, there are currently no rigorous outcome evaluations of such initiatives.

It is evident from both reviews (Whitehouse and McCabe, 1997 Burtney et al Forthcoming) that a variety of models and practices exist but the absence of rigorous, well-conducted evaluation makes it difficult to conclude what constitutes best practice for RSE delivery for people with intellectual disabilities. The research evidence would suggest that different approaches and strategies to providing RSE and to promote sexual health among people with intellectual disabilities may be required. A consistent theme in the research literature is the importance of involving people with intellectual disabilities, their families and the professionals who work with them to assess the information and support needs, and to tailor the response to meet these needs.

2.9 Conclusions

In 1995 Rachael Martin explored the barriers preventing people with disabilities in Ireland from expressing and enjoying their sexuality to the full. The report examined sexuality issues for people with disability through the family, education, mainstream health services, specialist sexual and reproductive services, residential services and non-governmental organisations and made the following recommendations:

- Specialised education and training along with counselling must be available to assist parents to deal with sexuality issues.
- Opportunities for sexuality awareness training must be made available for persons with a disability.
- The Department of Education must ensure that all resources include positive images of disability and that all resources should be produced in accessible forms.
- Training centres must develop and implement sexuality education in accordance with standards to be drawn up by an appropriate government agency.

- Disability training must become an integral component of training for all whose work impacts on the sexuality of people with a disability.
- In-service training particularly for educators, disability professionals, healthcare professionals, such as doctors, GP's, social workers and counsellors; general health service staff including receptionists and ancillary staff and other professionals such as clergy and youth workers should be set up to enable staff to remain updated concerning issues.

It is evident from this review of the literature and from the findings of the survey that recommendations still hold for 2006.

The most definitive conclusion to be made from the literature is that there is no cohesive or national approach in relation to RSE provision for persons with an intellectual disability. The literature suggests that many people with an intellectual disability are receiving little sexuality education, with staff and carers either ill-prepared or reluctant to address issues of sexuality. Although there is greater emphasis on the legal rights of persons with intellectual disabilities we still have little information on the sexual knowledge or feelings of individuals with intellectual disability or the effectiveness of educational programmes to alter this knowledge and feelings (McCabe & Schreck 1992, Garwood & McCabe, 2000).

However, a number of important threads emerge from the literature which maps out potential areas for further exploration and attention including policy and staff development, along with recommendations for developing comprehensive RSE programmes for people with intellectual disabilities.

In terms of policy and organisational input, there is a need to develop clear policies and guidelines which are evidence-based to support staff and help build effective services. Alongside policy, staff development is essential. As well as a willingness on the part of staff to be involved in RSE delivery appropriate staff training is essential to

the maintenance of good practice models, increasing confidence and competence levels and encouraging collaborative work practices.

In thinking about RSE courses, the literature firstly suggests a need to focus on increasing positive attitudes in relation to sexuality as well as improving knowledge. RSE must not only cover issues such as contraception and pregnancy but also seek to improve experiences of sexual and personal interactions, validation and connection. RSE should be rights based with language and resources focusing on ability, potential, confidence and self-actualisation rather than disability.

Secondly, delivery approaches could be developed to assist in the transfer of skills and knowledge to situations outside the learning environment and which focus on helping participants increase self-confidence and their ability to relate to others.

Thirdly, pragmatic approaches to RSE that sees sex as a normal aspect of life have been shown to be the most effective method of programme delivery and involving parents or caregivers as it will appropriately encourage greater awareness of issues involved and assist in this process.

Finally, all the literature examined, strongly recommends appropriate evaluation to be a fundamental requirement of any course delivered. Therefore, greater emphasis needs to be placed on the evaluation methodologies of all programmes carried out and not just on the development of models.

What is also evident from the literature is the lack of information on the situation in Ireland. Little is known about levels of sexual health knowledge among people with intellectual disabilities, staff attitudes towards sexuality, staff training and qualifications to deliver RSE programmes, all of which are important to improve the sexual health of people with intellectual disabilities. While this research can not address all of these issues, it goes some way to addressing issues relating to staff training by mapping out the current situation in Ireland in terms of existing RSE practice, identifying staff qualifications and previous training in this area, and models of RSE delivery.

3. Survey of Disability Agencies

3.1 Introduction

The following section outlines the methodology for use in the study, the population chosen and the particular methods employed.

3.2 Research Statement:

The current status of sexual health promotion and practice for people with an intellectual disability in Ireland.

3.3 Survey Procedures

Self-completion questionnaires were sent to 152 disability agencies across Ireland. Due to the potentially sensitive nature of the subject matter, confidential questionnaires were used as a means of encouraging honest responses. It was also considered likely to lessen the possible bias of a group response particularly as respondents were being asked to self assess training competency and confidence levels.

The self completion questionnaire examined staffs' qualifications, past training, and future training needs, and explored the training models used, including topics covered, mode of delivery and materials employed. Questions were a combination of pre-coded, closed, filter and open-ended questions (See Appendix 1 for a copy of the questionnaire).

Respondents were also invited to be involved in a follow-up telephone interview to express further views on the issues raised in the questionnaire. Telephone interviews drew out specific points from the responses made.

3.4 Population Selection

The questionnaire was administered on a nationwide basis. In order to maximise access to appropriate personnel, prior to the distribution of the postal questionnaire telephone contact was made with relevant agencies to identify key staff contact details. Furthermore, agencies were encouraged to copy the questionnaire and circulate to appropriate staff within organisations.

3.5 Questionnaire Description

The survey tool was a self-completion questionnaire divided into four sections. Section 1 of the questionnaire concentrated on the organisation and included questions on the type of organisation, number of service users, whether RSE policies and /or training is delivered and reasons for non delivery of RSE. This section questioned whether respondents considered RSE as important for their service users, what they felt is required within their organisations in order to deliver RSE, and their interest in obtaining training in RSE facilitation.

Section 2 of the questionnaire concentrated on the training needs of respondents who deliver RSE programmes. Questions explored what specific training had been undertaken and qualifications held. Respondents were asked to rate their views on the effectiveness of their previous training in enabling them to facilitate sexual health promotion work. Respondents were also asked to rate their own comfort and competency as sexual health promoters. Questions 13 to 16 pertained only to those respondents who indicated that they have received specific training in order to deliver RSE training.

Section 3 of the questionnaire focused on current programme delivery. A range of pre-coded questions examined the topics covered in programmes, the method of delivery and the training materials/manuals used to assist delivery. Question 25 was broken into three parts; a, b and c and investigates the number of service users in receipt of programmes, their age range and the level of intellectual disability.

The final section of the questionnaire was concerned with respondents' views on RSE provision. Respondents were asked to indicate from a list of providers who they thought was most appropriate to deliver RSE and to provide reasons for their selection. A further question asked respondents to indicate on a scale of "excellent, good, adequate, or poor" how they regard the general level of Relationship and Sexuality Education offered to persons with an intellectual disability. Finally, an open-ended question invited respondents to give their opinion on the conditions necessary for the delivery of good relationship and sexuality training.

4. Survey Findings

A total of 244 questionnaires were sent to staff working at 152 disability agencies. A snowballing sampling approach was also used whereby staff in receipt of questionnaires were requested to copy the questionnaire to relevant staff. Of the 167 questionnaires returned, 16 were photocopies resulting from this snowballing technique. Given this methodology it is difficult to measure the exact response rate. However, the number of questionnaires issued (244) plus the 16 photocopies returned results in a total of 260 questionnaires issued, giving a known response rate of 64%.

4.1 Respondent Profile

The majority of respondents, 70% (n=116) worked with Intellectual Disability services. Special school staff accounted for 10% (n=17) of questionnaires returned and others accounted for 20% (n=34) of respondents. Examples of other working settings included training services, residential housing and advice and information services.

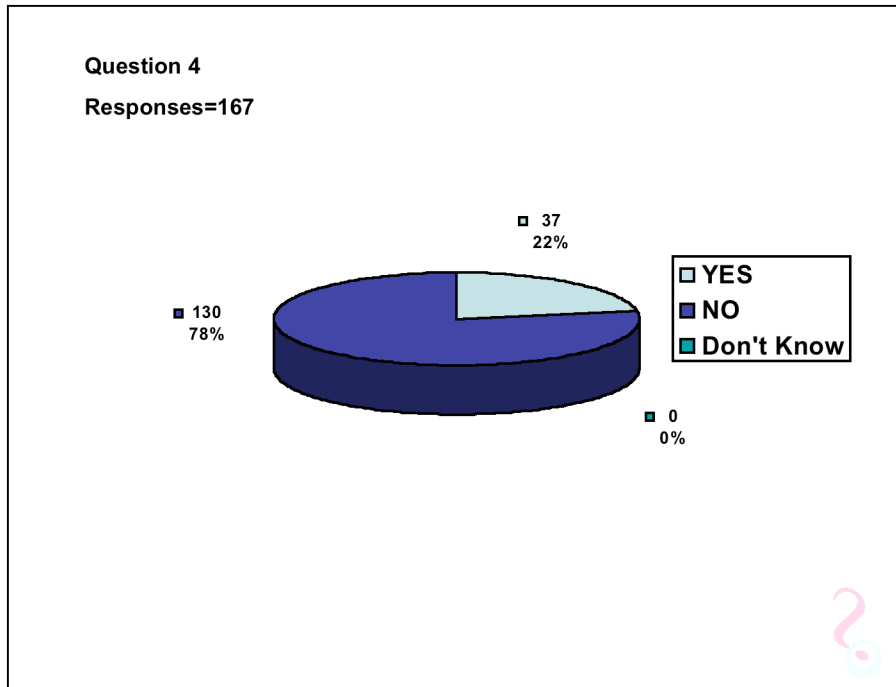
Just under half (46%) worked in organisations providing services to between one hundred and two hundred individuals with intellectual disabilities, and just under a third (38%) worked with organisations providing services to under 100 individuals with intellectual disabilities.

Most respondents worked with service users over the age of eighteen with 43% of service users between the age of eighteen and forty years. Only 10% of respondents had clients under the age of eighteen years.

4.2 Policies and Training

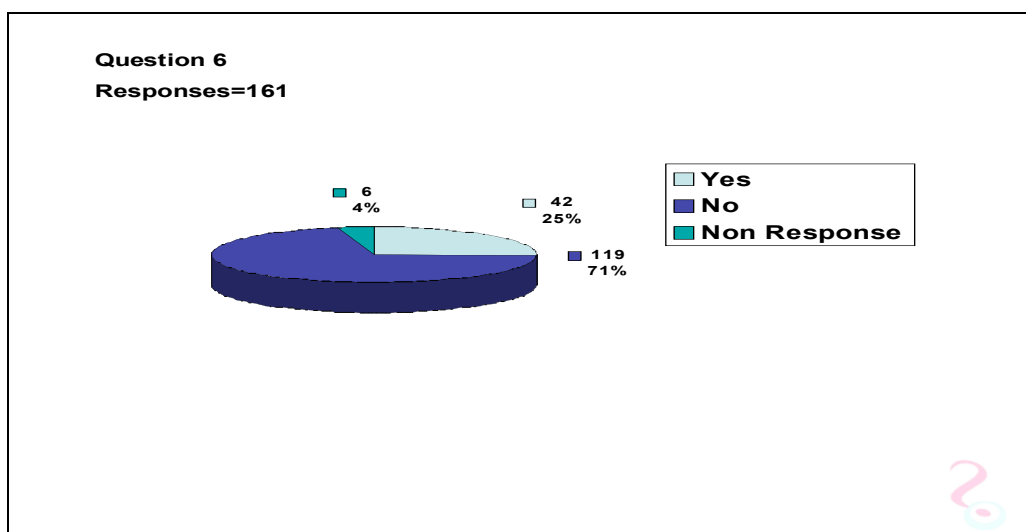
In response to the question on in-house training policies in relation to RSE delivery, just over three quarters (78%) of respondents had **no** in-house training policies in relation to RSE delivery. However 19% stated that in-house policies were currently being developed (see Figure 4.1).

Figure 4.1 In house training policies



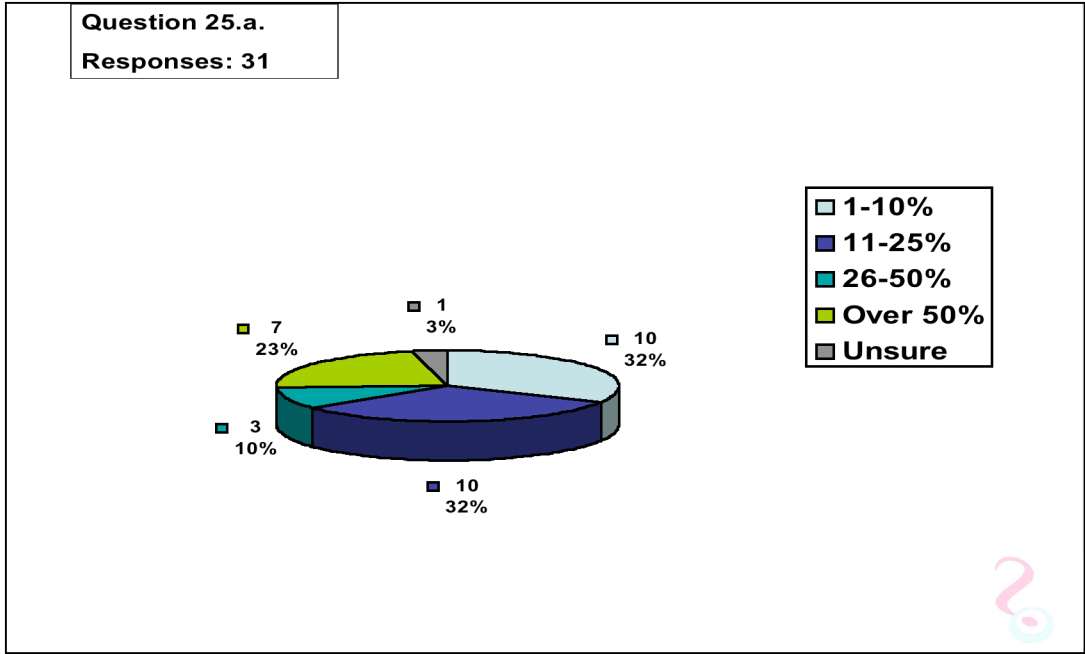
Just under three quarters (71%) of respondents indicated that their service did not provide RSE to its service users. Only a quarter (25%) of respondents reported that some form of RSE was delivered. (See Figure 4.2) A total of 6 respondents did state that individual ad-hoc interventions are made but that they are usually a response to inappropriate behaviours.

Figure 4.2 Availability of RSE



Among the 31 respondents that indicated that RSE was currently available on a regular basis (rather than ad hoc in response to adverse behaviour) within the organisation, less than a quarter (23%) reported that training was delivered to over 50% of their client group (See Figure 4.3)

Figure 4.3 Percentage of service users in receipt of training programmes



The majority of service users in receipt of RSE were over 18 years of age. This finding is not surprising as the majority of service users that respondents work with are over eighteen.

Where the service provided RSE, the majority of client groups were in the mild to moderate intellectual disability category. Only 13% of respondents indicated that their service was provided to clients with severe intellectual disability (see Table 4.1).

Table 4.1 Level of Intellectual Disability among those in receipt of training (Q25c)

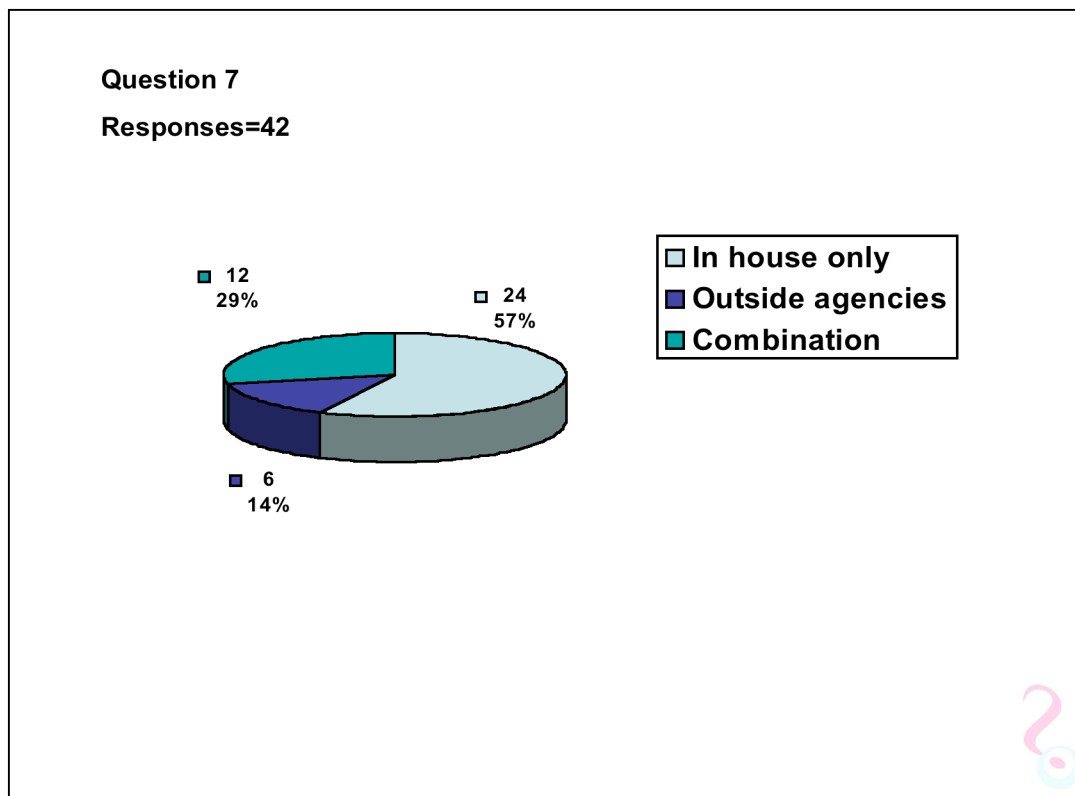
Ability Level	No	%
Mild	27	87
Moderate	24	77
Severe	4	13
Profound	0	0

Base n=31 (respondents who indicated that service provided regular RSE)

4.3 RSE Delivery Issues

Respondents were asked to indicate who delivers the RSE. Of the total of 42 (25%) respondents who work in an organisation where some form of RSE is delivered (on regular or ad hoc basis), just over half (57%) stated that training was delivered by in-house trainers. A further 14% indicated that outside agencies delivered the training and 29% used a combination of both inside trainers and outside agencies (see Figure 4.4).

Figure 4.4 Who Delivers RSE?



Of the 42 respondents who reported that some form of RSE was available to service users, just 29 of these have given details of specific issues / topics covered (Table 4.2). This may in part be due to the fact that 6 (14%) use outside agencies for RSE delivery and a further 12 (29%) use a combination of internal and external trainers, thus knowledge of what is covered may be limited. All respondents reported covering issues on Feelings and Emotions, Body Parts and Public and Private. A majority of respondents also covered all topics as stated.

A further 14% reported covering Stay Safe issues and Appropriate and Inappropriate Sexual Behaviour issues respectively. Dating Skills was included by 10% of respondents and Marriage / Living together by 3%. Pregnancy was also covered by 3% and Sexual Intercourse by 7% of respondents. Although this would appear low, it does not exclude the possibility that such issues are covered along with other topics, such as contraception or sexual expression.

Table 4.2 Issues/topics covered in RSE programmes

Issues/Topics covered in RSE	N	%
Body parts	29	100
Public and Private	29	100
Feelings and Emotions	29	100
Making choices	27	93
Contraception	25	86
Friendship skills	25	86
Sexually Transmitted Infections	24	83
Puberty	24	83
Masturbation	24	83
Rights and Responsibilities	23	79
Communication skills	22	76
Self awareness	22	76
Confidence building	22	76
Reproduction	22	76
Gay/Lesbian relationships	22	76
Life stages	21	72
Sexual expression	20	69
Parenting	15	52
Other	10	34

Base: n=29 (from possible 42 respondents)

Multiple responses, therefore percentages may not total 100%.

Respondents were also asked about the style of delivery used for the training. Table 4.3 demonstrates a combination of delivery methodologies in use, with group work accounting for 93%, discussion groups 83% and video presentations 72%. Other methods of delivery include role-play, games, projects, and an anonymous topic box.

Table 4.3 Style of Programme Delivery

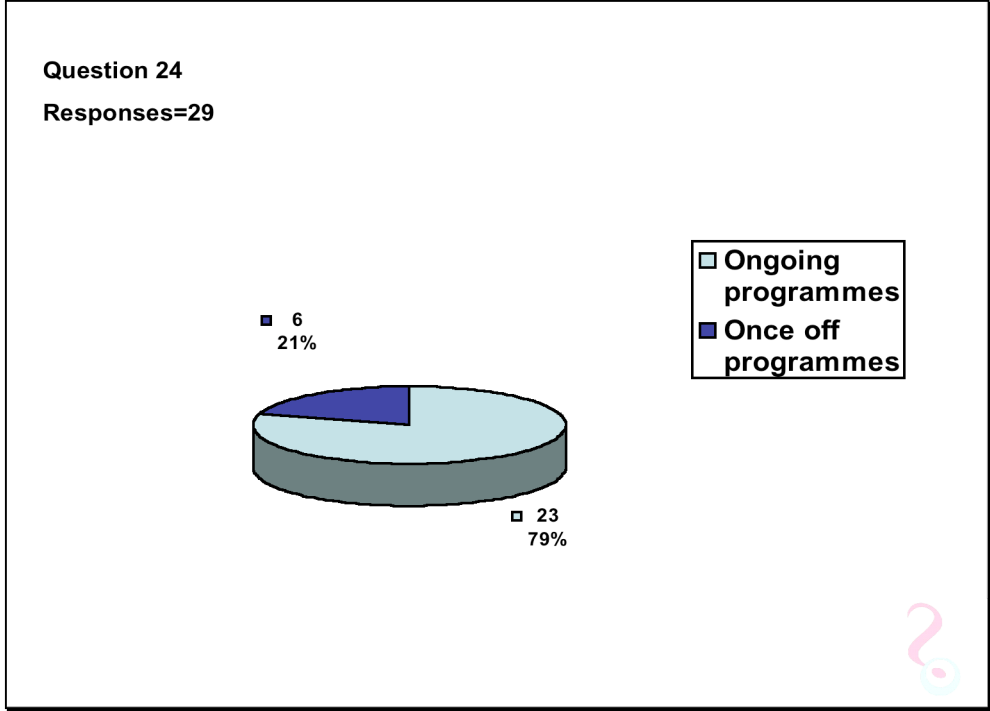
Style of Delivery	N	%
Group work	27	93
Discussion Groups	24	83
Video	21	72
Presentations	19	66
Question and Answer sessions	16	55
Individual	15	52
Ad hoc / in response to particular incidences	13	45
Art / Drama	8	28
Other	6	21

Base n=29

(Multiple responses, therefore percentages may not total 100%).

The majority (79%) of respondents reported that where RSE was delivered to service users it was provided as part of an ongoing training programme. Two respondents who reported offering once-off sessions indicated that courses were currently being piloted (See Figure 4.5).

Figure 4.5 Programme duration



Respondents reported using a broad range of materials to support their training (see Table 4.4). While just under a third of respondents (31% n=9) reported using Living Your Own Life, The Sex Education and Personal Development Resource for Special Educational Needs by Ann Craft and Hilary Dixon, no key texts or materials are used across the board.

Table 4.4 Training materials/manuals used to assist in training delivery

Title of Training Material	N	%
Living Your Own Life, The Sex Education and Personal Development Resource for Special Educational Needs – Ann Craft & Hilary Dixon	9	31
Understanding the Facts of Life, S. Meredith & R. Gill – Usborne	5	17
A Programme of Social, Personal and Health Education, Bí Follain, Mid-Western Health Board	4	14

Title of Training Material	N	%
Talking Together About Growing Up –Lorna Scott & Lesley Kerr-Edwards. FPA.	4	14
Picture Yourself, Social and Sex Education for People with Learning Disabilities – Hilary Dixon & Ann Craft	3	10
Making It Personal – Paul Cambridge	3	10
Freedom – RSE for Students with a mild Learning Disability, Brothers of Charity Personal Development Programme	3	10
Sex in Context – Ann Craft & Caroline Downs	2	7
Sex and The 3R's – Michelle McCarthy & David Thompson	2	7
Chance to Choose – Hilary Dixon (LDA)	2	7
Slides – Life Horizons, Kempton W, Stanfield J, Camera Talks Production.	2	7
Sexuality and Mental Handicap – Educators Resource Book, Hilary Dixon	2	7
Bawnmore Personal Development Programme	2	7
Lets Do It – Lesley Kerr-Edwards	2	7
Becoming a Woman – Emma Cooper (Pavilion)	1	3
Black and White Guides – Family Planning Association	1	3
Taught not Caught Resource Pack, strategies for sex education. Eds. Hilary Dixon & Gill Mullinar. Learning Development Aids.	1	3
Education Pack from York House UK	1	3
Health Promotion Department literature	1	3
Growing Up – Veritas	1	3
Brook Advisory Service information, UK	1	3

Title of Training Material	N	%
Contraceptive Display Kit	1	3
Torso Model	1	3
Condom Training Model	1	3

Base N=29

The above responses are taken verbatim from the questionnaires and as such may contain discrepancies and overlap in reporting

4.4 Respondents Training Issues and Needs

Of those currently delivering RSE programmes the majority (80%) said they had received some form of training to assist them in delivering programmes. Table 4.5 below outlines the type (where specified) and duration of courses attended by 31 respondents who had received training. The majority of those in receipt of training had, where specified, undertaken just 1 or 2-day courses as the total amount of training undertaken to equip them to deliver programmes.

Table 4.5 Type and Duration of training received

Course	Duration	N	%
Irish Sex Education Network	1 Day	19	61
Irish Sex Education Network	2 Day	12	39
Irish Family Planning course,	2/3 Day	8	26
Workshops (Peter Dorai Raj) (unspecified)	Unspecified	6	19
Sex Matters Training (Gert Job) (unspecified)	Unspecified	6	19
In-house training workshops (unspecified)	Unspecified	5	16

Course	Duration	N	%
Sexuality and Relationships course (Dr Shay Caffrey)	10 Day	4	13
Workshops (unspecified)	1&2 Day	3	10
Granada Institute Relationship and Sexual Awareness Training.	5 Day	3	10
Waterford Institute of Technology (unspecified)	Unspecified	3	10
Working with Parents and Children with ID (Gert Job)	Unspecified	2	6
Bawnmore Personal Development Programme	Unspecified	2	6
Professional training in clinical psychology	Unspecified	2	6
Dealing With Inappropriate Sexual Behaviour (Gert Job)	Unspecified	1	3
Drama based activities for RSE course	2 Day	1	3
Training course (unspecified)	10 Day	1	3
Other (unspecified)	8 Day	1	3
Generic training	Unspecified	1	3
Department of Education courses (unspecified)	Unspecified	1	3

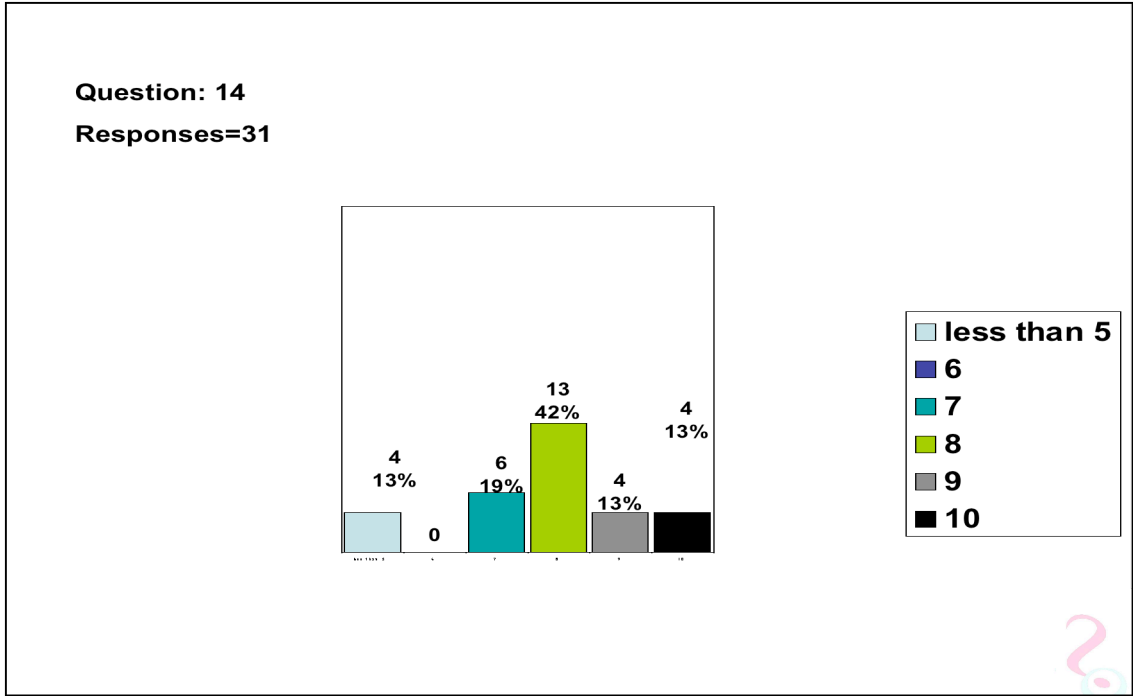
Base n=31

Course details are as taken as verbatim from responses and as such may result in overlap or inaccuracies.

Respondents were asked to rank the effectiveness of their training in enabling respondents to facilitate training. Figure 4.6 indicates the perceived level of

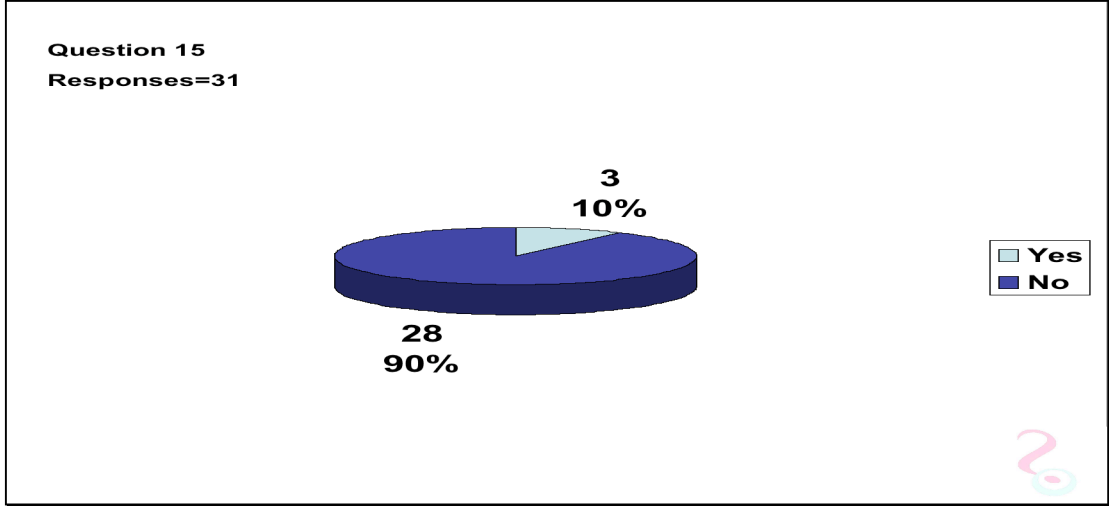
effectiveness of courses respondents had undertaken to enable them to deliver training. A scale of 1 to 10 was used to determine the effectiveness of courses with 1 being not at all effective and 10 being very effective. The majority felt that courses undertaken were generally effective in enabling them to deliver training with 21 indicating a level of 8 or higher on the scale. A total of 4 respondents indicated a rating of less than five on the scale. It should be noted that satisfaction levels with training received might be considered high in the absence of alternative available training.

Figure 4.6 Effectiveness of courses in enabling respondents to facilitate training



Respondents were asked about their professional qualifications in the area of Relationship and Sexuality Education. Only three of the 31 respondents (10%) reported having a professional qualification in Sexual Health Promotion or Sexology (see Figure 4.7). The 3 respondents had gained their qualification in RSE delivery through a certificate level course from Waterford Institute of Technology. The course title was unspecified but it is assumed that this course relates to one of the courses run by J. Woolf & Associates through Waterford Institute of Technology.

Figure 4.7 Professional qualifications in area of RSE



Eighteen (62%) respondents who delivered sexuality training indicated that they had updated their skills within the previous twelve months. Table 4.6 indicates that the training received as updates, mirrors responses made to question 13, suggesting that this is the total of training received, that most of this training is workshop based and comprises an average duration of just 3 days.

Table 4.6 Types of training updates

Details of Training Updates	No	%
Workshops	17	94
In-house	2	11
Designing a RSE programme	2	11
Information	1	6
Conferences	1	6
Seminars	1	6
Facilitator training	1	6

Details of Training Updates	No	%
In-house on application of policy guidelines	1	6
Self Education	1	6

Base n=18

(Multiple responses, therefore percentages may not total 100%.)

Competency levels in RSE delivery

Questions 19 and 20 requested respondents to indicate their perceived comfort and competency levels in delivering sexuality education on a scale of 1-10 where 1 is very uncomfortable and 10 is very comfortable.

As demonstrated by figure 4.8 only 1 respondent indicated a comfort level of less than 5, whilst 28 (90%) indicated comfort levels of 7 and over. Figure 4.9 indicates competency levels as high with 23 (75%) feeling competent to very competent. This was a surprising result, given the relatively low level of training received.

A response bias in relation to both these questions is possible as respondents were asked to self evaluate their levels of comfort and competence. When compared to responses given in question 21, indicating training needs, respondents had a wide range of training needs suggesting their competency levels may not be as high as indicated.

Figure 4.8 Comfort levels in RSE delivery

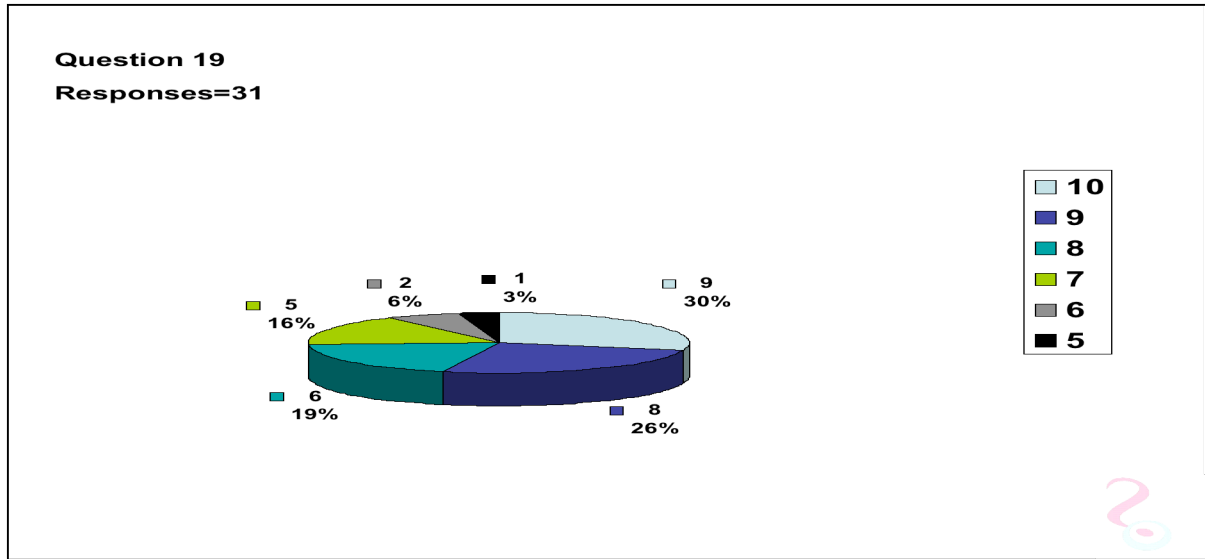
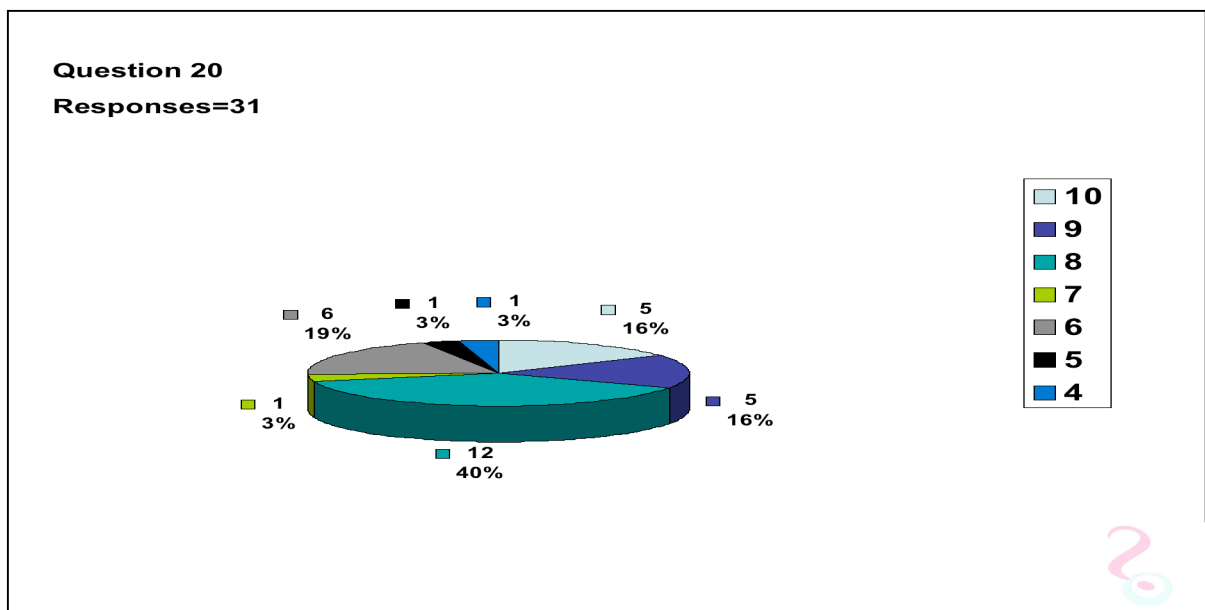


Figure 4.9 Competency levels in RSE delivery



Training Needs

Respondents were asked to describe their training needs to support them in the delivery of sexual health training. Table 4.7 shows a wide range of training needs reported by those currently delivering training, suggesting a need for broad based

training programmes for trainers. A number of respondents indicated that they are in the process of developing policies / guidelines and training programmes.

The specific training requirements suggest a need for professional or qualification training in RSE delivery as well as a network for individual trainers to share ideas. Particular skills for working with specific needs as well as general training methodologies including evaluation and assessment were also stated.

Table 4.7 Current training needs in relation to RSE

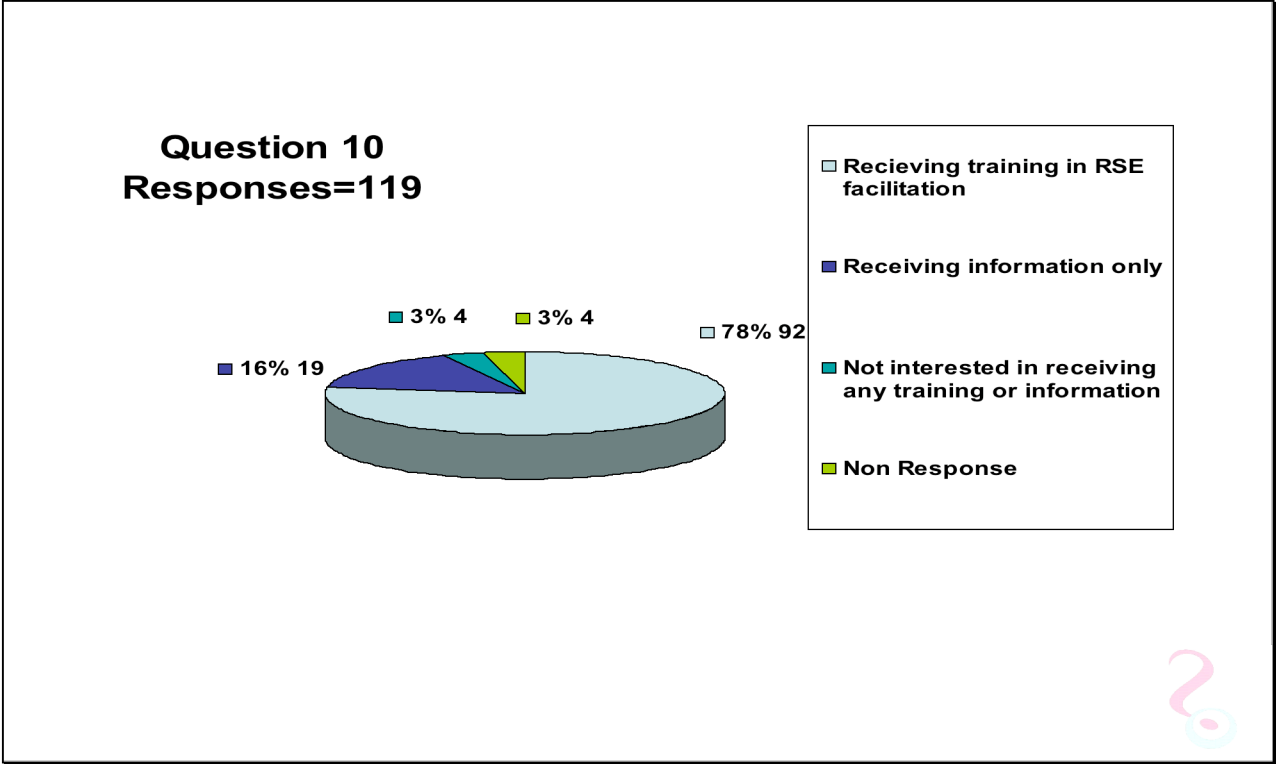
Training Needs	No	%
Professional/ qualification/certificated training course	8	28
Networking/ sharing ideas	5	17
Skills for work with profound learning disability/complex communication needs/non verbal	4	14
Acknowledgement of RSE delivery as part of role/ time allocation	4	14
Effective reviewing/ evaluation/assessment	4	14
Access to materials/training aids	3	10
Parenting skills/relationship training	3	10
Boundaries/ methodologies	2	7
Counselling /psychotherapeutic skills	2	7
Training methodologies	2	7
Greater access to visual information	2	7
Programme development/methodologies for physical and sensory disabilities	2	7

Training Needs	No	%
More practice / experience	2	7
Supervision and Support	2	7
Policy development within organisation	1	3
Use of storytelling in training	1	3
Facilitation around feelings and sexuality	1	3
Working with people within autistic spectrum	1	3
Information on Sexually Transmitted Diseases	1	3
Unclear	1	3
None	1	3

Base n = 29 (Multiple responses, therefore percentages may not total 100%)

Figure 4.10 demonstrates considerable interest in receiving training with 78% of those not currently offering programmes expressing an interest in undertaking training in RSE facilitation. A further 16% would like to receive information only.

Figure 4.10 Interest in staff training for RSE delivery

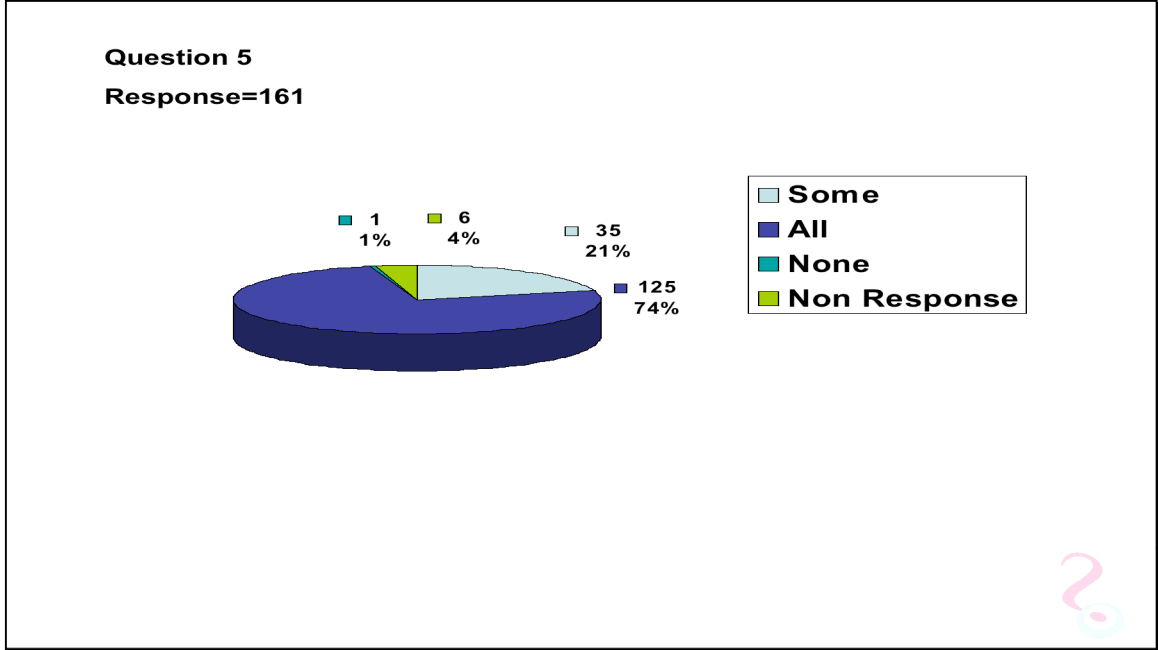


4.5 Respondents Opinions and Views of RSE for People with Intellectual Disabilities

The final section of the questionnaire concentrated on eliciting respondents’ views and experience of RSE for people with intellectual disabilities.

Figure 4.11 shows a majority of respondents (74%) felt that RSE was important for **all** their service users. A further 21% felt RSE to be important for **some** service users. There was a non-response rate of 4%.

Figure 4.11 Considered importance of RSE

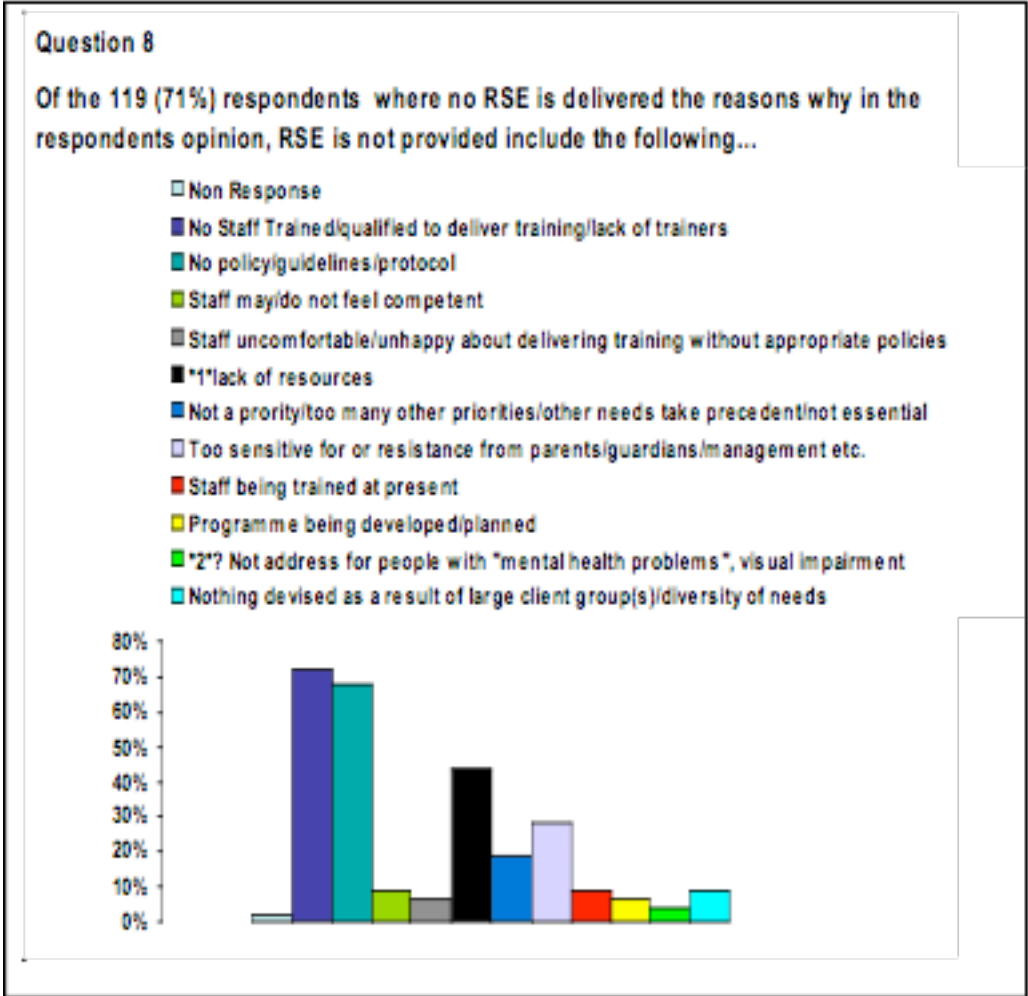


A total of 152 respondents gave reasons for their answer. Reasons given for RSE to be delivered to **all** of their service users included the need for clients to develop relationships, to increase awareness, to improve the quality of life and because service users had indicated a need for RSE.

Reasons given for why only **some** service users should receive RSE included the feeling that not all are capable of understanding or have too severe a disability. In some cases RSE is provided in school settings. Some service users were considered by respondents to have no difficulties or no interest in receiving sexuality education and some should be given RSE because they exhibit inappropriate sexual behaviours.

Where **no** RSE provision exists, figure 4.12 shows the main reasons stated by respondents for non-delivery as, lack of both trained staff and policies, coupled with a lack of resources and the perception that it is too sensitive an issue for management / families and with other priorities taking precedence. A small number of respondents also felt that some staff might feel uncomfortable about delivering RSE.

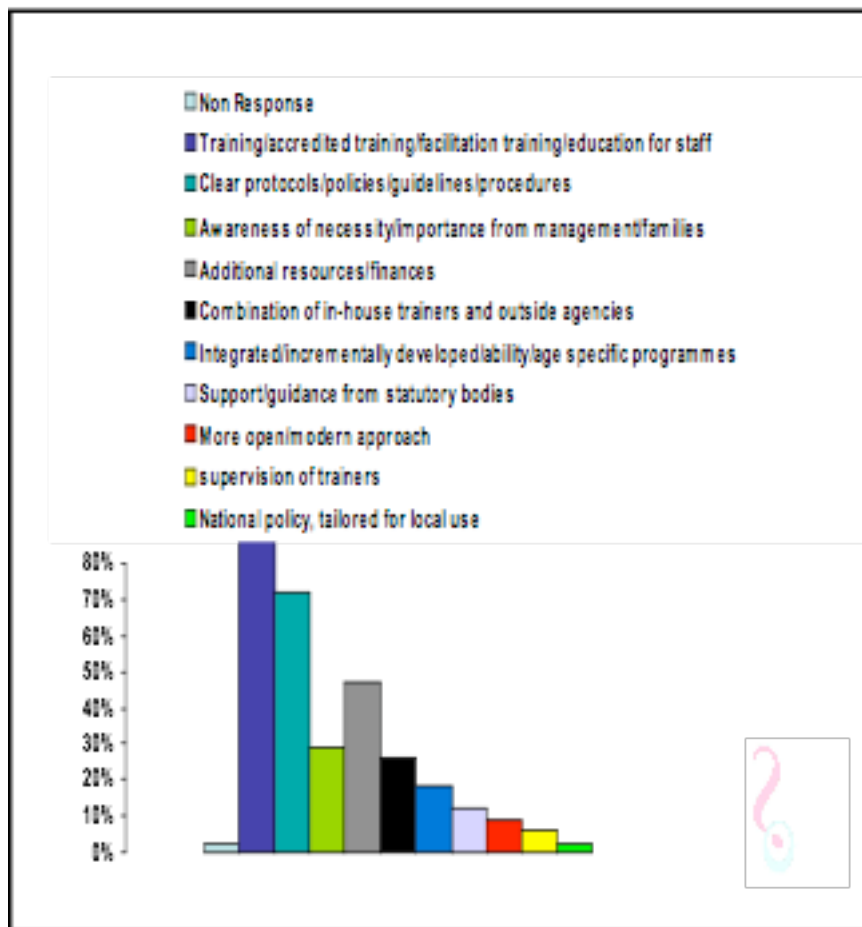
Figure 4.12 Reasons for non-delivery of RSE



Multiple responses, therefore percentages may not total 100%.
 Responses = 117.

Figure 4.13 outlines respondents' views on the most important requirements seen as necessary for delivery of RSE. This echoes the findings from question 8, perceiving the important requirements to include training and / or accredited training, the availability of clear policies and guidelines and additional resources. Acknowledgement of the importance of RSE to the lives of persons with an intellectual disability and the ensured support from management, families and other staff are also highlighted.

Figure 4.13 Necessary requirements for RSE delivery



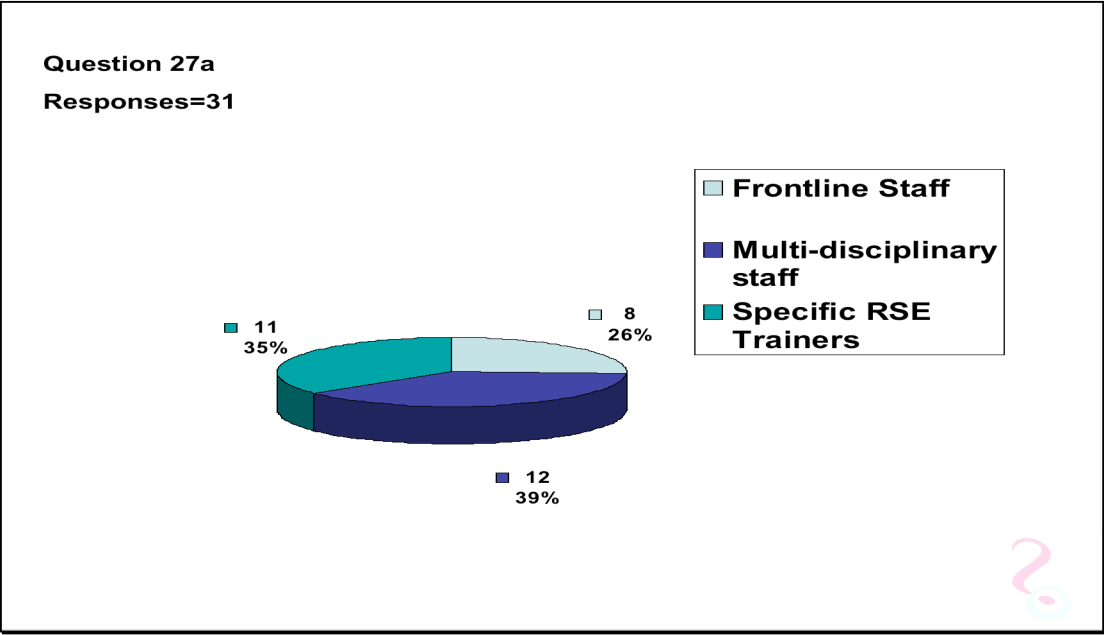
Responses=117.

Who should deliver RSE training?

Delivering Programmes

Respondents were almost equally divided about who they thought most appropriate to deliver training (see figure 4.14) with 26% choosing frontline staff, 39% multi-disciplinary staff and 35% specific RSE trainers.

Figure 4.14 Who is most appropriate to deliver Relationship and Sexuality training?



Reasons for believing frontline staff to be most appropriate included the feeling that frontline staff have a greater knowledge of their client group and are thus more accessible and approachable. There was a belief that delivery by front line staff would result in greater consistency in the delivery of RSE. Frontline staff are considered to be more in touch with individuals and can integrate RSE work into the day to day programmes and lives of service users. There are more opportunities for ongoing discussions and the mystique can be removed from a subject usually taught in isolation.

“If the people who deliver are on the ground, if there is a problem for any client he can speak about it right away without waiting for a meeting to be set up”.

“Know students best. I (psychologist) deliver programmes with class teacher. Works well. Building up teachers confidence and expertise”.

Reasons given for feeling specific Relationship and Sexuality trainers to be most appropriate to deliver training included the belief by some that it can be difficult for

frontline staff to deliver RSE programmes as it affects their interaction and relationships with service users. Respondents felt trainers need to feel competent, comfortable and objective delivering such programmes. There is a perceived risk of ones own values getting in the way of training delivery and thus respondents feel anyone undertaking programme delivery must have a real interest in the subject, be adequately trained and feel supported in what they are doing. Respondents also expressed concerns regarding possible litigation.

“Requires trainer to be objective and comfortable in giving this training”.

“Trainers need to be aware of their own attitudes / levels of comfort and prejudice around this area. The training provides a place for exploration of this”.

“Without the protection of strong organisational policies frontline staff, who best know service users are too exposed to possible litigation”.

Reasons for feeling a multi-disciplinary approach to be most appropriate in training delivery include the belief that choice is important to service users and that they should have the choice of using the most comfortable and approachable method for them. A multidisciplinary approach is also seen as enhancing communication. Respondents suggest that frontline staff cover issues of rights and responsibilities whilst specialist RSE staff might undertake discussions of a more sensitive nature.

“A multidisciplinary approach can enhance communication. It is important to have a shared vision, knowledge and comfort”.

“Aspects of RSE including assertiveness, rights and responsibilities etc. are best delivered by frontline staff, who

through their knowledge of group members, can facilitate discussion related to real life experiences. Multi-disciplinary staff, through their objectivity, are better placed to deliver information on sexually sensitive topics e.g. masturbation”.

“RSE is better delivered as a normal part of the school curriculum. Students sometimes relate better to or confide in different members of the multi-disciplinary team”.

The conditions necessary to encourage the delivery of good Relationship and Sexuality training models were defined under a number of themes that included policies and training, organisational support, parental and staff communication, trainer support and supervision, the training environment and specific training and preparation needs.

Respondents expressed a strong need for more adequately trained personnel to deliver programmes with some respondents feeling a need for specialised RSE staff to co-ordinate and support training. Combined with this is the need for ongoing support and supervision for trainers, clear and consistent organisational policies, appropriate staff guidelines and adequate resources.

“Good resources, a planned programme, trained personnel”.

“Strong organisational policies combined with regular training and support”.

“Comprehensive organisational policies and staff guidelines”.

“Facilitators must be comfortable and confident with the teaching material”.

“Availability of or access to specialists for guidance”.

Organisational support both on the part of management and other staff was seen as being a necessary requirement for good RSE delivery. In particular respondents called for adequate time allocation to allow trainers to both prepare and deliver courses.

“Endorsement and encouragement and backing by management”.

“Support from all staff in centre, particularly management”.

“Empowering staff with good support materials in an atmosphere of mutual respect and encouragement”.

“Support from the organisation. Financial resources for materials and ongoing training”.

“Funding-follow up sessions i.e. not just once off”.

Communication with all stakeholders including service users, families and staff is considered necessary as it is felt that good communication builds high levels of trust. Many respondents felt the need for parents / carers / families to be involved in the process and it was felt that it was important that parents valued such training and remained open minded. Education for parents and other staff was also recommended.

“Excellent communication with all the stake holders, service users, families and staff”.

“I think sexuality and rights of a service user need to be valued. There needs to be a commitment by all staff and serv-

ices to the area of relationships and sexuality. No point in having training if service users can't explore and have real relations".

"Importance of such programmes must be valued by parents and facilitators".

"Willingness of parents and staff to be open minded".

The training environment was also seen as an important factor in encouraging best practice in RSE delivery. Respondents felt privacy and safety as essential elements of the training environment, as well as an assurance of confidentiality. Small groups were seen as necessary along with male and female trainers working in pairs. A non-judgemental attitude on the part of the trainer and a willingness to answer all questions were considered key elements of good delivery.

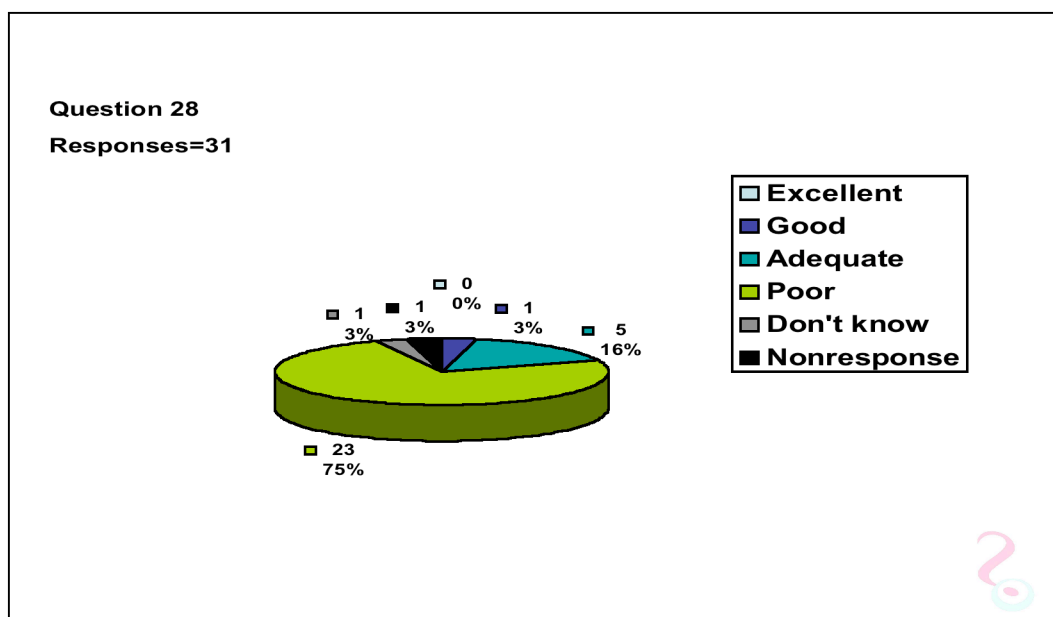
"Safe environment, trust and confidentiality. Client has ability to give consent".

"An emphasis on personal development and ethos of rights and responsibilities in the service. Delivery should be focused on communication needs of clients and matched to their ability to give consent and sensitive to development needs".

"Openness, safety, strong boundaries, confidentiality".

Figure 4.15 shows that of respondents who currently offer Relationship and Sexuality Education (75%) feel the general level of RSE delivery in Ireland to be poor.

Figure 4.15 Quality of Relationship and Sexuality Education delivery in Ireland



4.6 Additional Comments

Additional comments were made by 9 respondents and comments which included a call for the development of national policies, the need for RSE to be part of the school curriculum with relevant topics delivered at developmentally appropriate stages and the importance of approaching RSE as ongoing throughout the life stages.

“There is a need to lobby nationally to repeal the Criminal Law (Sexual Offences’ Act (Section 5) which make sex between individuals with learning disabilities illegal and to introduce legislation around consent and vulnerable adults-supportive legislation that emphasises building capacity to consent”.

“I feel that we are just at the very earliest stages of our awareness of the needs of people with intellectual disability with regard to RSE. The legal situation e.g. the theoretical illegality of such persons engaging in sexual relationships is a major barrier to progress and to the comfort and safety of those already engaged in the facilitation of such programmes”.

4.7 Telephone Interviews

A total of 14 respondents agreed to be contacted for telephone interviews and contact was established with 11 of those. The following includes additional comments made by telephone respondents.

There was a general belief that a fear exists amongst organisations of the legal implications of delivering Social, Personal and Health Education (SPHE), which encompasses RSE in Ireland and that current law requires change. Some interviewees felt that there is a reluctance to develop such services beyond the most basic. It was felt that emphasis for training is placed primarily on those with a very mild intellectual disability and respondents felt that appropriate programmes should be offered to those with more profound intellectual disabilities.

Interviewees felt that they would like to see structures in place which would provide an increased link between RSE training delivered in school settings and residential services so that specific issues arising from such training could continue to be addressed in a broader care setting. Respondents did not feel they knew enough about what was being offered their service users in school and thus felt they could not support learning and address individual needs.

A team approach to RSE delivery was considered a necessary requirement. Training is seen as important for service users whatever the level of intellectual ability and should be delivered throughout life stages. Furthermore, many felt that training should be offered by a range of staff and not be solely the remit of specialised trainers in a classroom type setting. All team members should be capable of and comfortable addressing issues of human sexuality with service users at all levels.

Respondents felt that staff need to be comfortable with the issue of human sexuality. Currently many bring their own hang-ups and beliefs to the work situation. One respondent felt that this issue should be addressed at interview stage.

Respondents felt that different inputs are required at different developmental stages throughout life and that different inputs are required for differing levels of ability. Access to adequate resources was also cited as having an influence on training offered and the need for two trainers, male and female, to deliver training was seen as a necessity.

5 Discussion

5.1 Introduction

The study examined both the level of RSE delivery and details of current programmes offered in Ireland. The training needs of staff and their ideas in relation to the conditions and personnel which best support delivery of good RSE training models were also analysed. The following chapter outlines the key issues raised by the research and draws comparisons with the international literature.

5.2 The Organisations

Most organisations (78%) had no current in-house training policies relating to RSE delivery. Furthermore the availability of RSE training programmes to service users was also extremely low, with 71% of respondents stating that no such education was delivered to service user groups. Where sexuality training was available within organisations, 77% of respondents reported that RSE training was delivered to less than 50% of their service users.

The majority of respondents felt that the reason RSE is not provided is because of a lack of trained or qualified staff combined with a deficiency of policies and guidelines. Many perceived that RSE was not seen as a priority, or that other needs took precedence and the lack of existing policies within organisations lends support to this belief. Lack of resources was also cited as a reason for not delivering programmes thus supporting the view that RSE is not considered a priority. Some respondents felt that a more open and modern approach is necessary within organisations for RSE to be delivered. Some respondents suggested that organisations fear litigation, corroborating Browns (1994) findings. One interviewee felt that there was a reluctance to develop services beyond the most basic.

In order to deliver quality RSE programmes the development of comprehensive organisational policies was considered a priority by respondents. Combined with this was the need for planned programmes and adequate training for staff. Organisational endorsement and support was also considered an essential element for effective RSE education, as was the availability of adequate funding and resources and the involvement and support of parents and other staff. In addition respondents saw the need for regular supervision, access to specialists and sufficient time dedicated for preparation and delivery as central to the provision of training programmes. The international literature supports the views of respondents. It demonstrates categorically that the development of appropriate policies, the enhancement of links with and support from management, the availability of resources and the appropriate training of staff have an enabling effect on all concerned.

The majority of respondents (74%) felt RSE to be important for all their clients and the reasons given included a belief in the need for such training to be part of a continuum of education, that service users have an entitlement and a need for both Relationship and Sexuality Education and to improve quality of life. A main reason given for RSE to be delivered only to certain client is that not all clients are considered capable of understanding. On the other hand, lack of awareness, inappropriate sexual behaviour or habits as well as a feeling that some service users have no interest or no difficulties were also offered as reasons why only some should be offered RSE.

The limited availability of Relationship and Sexuality Education for those with an intellectual disability in Ireland reflects the findings from the international literature which demonstrates that many individuals with intellectual disability receive little or no RSE. The need for clear and unambiguous Relationship and Sexuality Education for people with a disability is generally regarded in the literature as a fundamental human right. However, most organisations in Ireland still have no policies and guidelines in place and a feeling exists that organisations do not consider Relationship and Sexuality Education to be a priority. Furthermore this study indicates that most respondents feel clearly unsupported at present as they are calling for adequate

course preparation and delivery time, increases in resources and organisational backing.

5.3 Programme Delivery

Of those currently delivering RSE most reported spending between 1% and 10% of their work in the delivery of programmes. The majority of programmes offered are delivered on an ongoing basis. A wide range of issues and topics are covered in current programme delivery. All respondents include topics on Body parts; Public and Private, Feelings and Emotions and a majority cover Contraception, Friendship Skills and Making Choices. Parenting issues are covered by 52% of respondents.

However, from the research there appears to be no standard curriculum or key texts used. A combination of delivery methods are used with many trainers including group work, discussion groups and use of videos as part of their programmes. This substantiates the recommendations from the international literature, which emphasises the need for both knowledge and skills development as essential components of RSE delivery.

The literature also highlights the need for individually tailored programmes and use of specific teaching aids. However, there is little evidence of such and little or no training materials available which are culturally specific. Currently, UK produced videos are used for training purposes. However, the pace and accents of these are regarded as unhelpful. Therefore Irish developed materials, particularly videos, are considered vital for delivery of training to Irish participants.

Respondents see training as needing to be delivered on an ongoing basis as individuals face new life changes, experiences and changing feelings. Messages also need to be reiterated and methodologies evaluated regularly. International findings support this and consider education programmes that view sex as a normal part of life as most effective. The literature also stresses placing greater emphasis on evaluation of methodologies.

Respondents appear almost equally divided in their opinions on who is most appropriate to deliver RSE. One reason for believing frontline staff to be most appropriate is that this method allows opportunities for ongoing discussions and removes the mystique from a subject often taught in isolation. Frontline staff are seen as having a knowledge of service users. In addition, they are considered more accessible and approachable to service users and would provide consistency.

Those who opted for specific RSE trainers as most appropriate felt that delivering such programmes affects frontline staff's interaction and relationships with service users. Respondents stress the need for training, particularly in relation to attitudes, values, comfort and competency levels of frontline staff and suggest that what is required is adequate training, objectivity and confidence from trainers. Such attitudes reflect the recommendations from the literature, which highlight the need to focus on increasing positive attitudes to sexuality, improving confidence and ability as well as increasing knowledge.

In considering a multidisciplinary approach to be most appropriate, respondents suggest that because such an option can enhance communication in that individuals respond to a range of trainers and approaches, a multidisciplinary model provides more choice for service users. Certain elements such as assertiveness are considered best delivered by staff that know group members well and can relate discussion around real life issues, whereas other staff are seen as better placed to deliver sessions on sexually sensitive topics. Telephone interviews support the idea of a multidisciplinary team approach and a number of interviewees expanded on this idea in suggesting that a team approach will allow for needs to be addressed throughout life by a range of staff, thus removing RSE from being solely a classroom experience.

5.4 Staff Training Issues

Some 31 (80%) respondents currently involved in the delivery of RSE programmes stated that they had received specific training in order to assist them in the delivery of

training. Many of those who specified the duration had attended training courses or workshops averaging between just 1 and 2 days. Responses suggest that courses attended are diverse and varied with no apparent homogeneity.

Satisfaction rates with courses are high, with respondents feeling that courses were effective or very effective in enabling facilitation of training. Over 50% had updated their skills within the previous twelve months. However, when compared with responses from question 12, it appears that this “update” accounts for the sum total of all training received in most cases. This is again a worrying finding as it indicates very low levels of staff training. Furthermore, it should be noted that satisfaction levels with training received might be considered high in the absence of any alternative training.

Comfort levels in delivering RSE were also high amongst this group and competency levels are only slightly lower. This again is a somewhat surprising response given the low levels of training undertaken. A methodological weakness here is noted as respondents were asked to self evaluate their levels of competence and confidence. When compared to responses given to the question on training needs, it was evident that most respondents had additional support needs which suggest that competency levels may not be as high as implied.

Survey respondents were very supportive of the provision of RSE programmes for people with intellectual disabilities. There was considerable interest from respondents who are not currently delivering RSE programmes to undertake training themselves with over three quarter (78%) of respondents indicating a wish to avail of RSE facilitation training, similar to the findings from the Ryan and McConkey (2000) study. It is likely therefore that reluctance to undertake delivery of RSE results from feelings of inadequacy and low confidence levels arising from lack of training in the area, a view supported by the literature. Results also show very low levels of RSE facilitation training amongst those currently delivering training and indicate a distinct need for more comprehensive training programmes for trainers.

Professional or certified training in RSE delivery and a network for individual trainers to share ideas were suggested as ways of meeting training needs. Adopting Chivers and Mathiesons' (2000) recommendation of accrediting staff that undertake RSE facilitation training would go some way to rectify this need. Particular skills for working with specific needs as well as general training methodologies including evaluation and assessment were also called for. In relation to the training environment, respondents outlined the need for a safe, secure and relaxed environment that adheres to a policy of clear ground rules and is respectful to the wishes of participants. Additional comments included the need to repeal the Criminal Law Sexual Offences Act, (1993 Section 5), which is considered to be a barrier to progress and a difficulty for personnel currently engaged in programme delivery.

6. Conclusions and Recommendations

The need for life-long sexuality and relationship education is now generally accepted as an important approach in sexual health promotion for everyone. However, findings from both the review of the available international literature and from the national survey of organisations working with people with intellectual disabilities in Ireland reveal a general lack of consistency in both the provision of RSE and in the training of staff to provide RSE. Findings from both the literature and the survey reveal that many individuals with intellectual disabilities are still not receiving appropriate education in relation to their sexuality, and where programmes are provided, many viewed the programmes to be of poor quality.

The majority of individuals who responded to the survey reported that their organisation had no training policies and did not offer specific sexuality training to service users. It is important to note that the majority of respondents felt that the provision of RSE was important for their service users and expressed a general willingness to undertake training in order to assist them deliver such programmes. The main reason provided by respondents for the lack of delivery was that RSE is not seen as a priority by organisations. Evidence for this is demonstrated by a general lack of training policies, appropriate resources, time allocation for programme delivery and endorsement by management.

Where training is provided, staff felt themselves to be both confident and competent. However, many staff expressed training and support needs, and the actual amount of RSE facilitation training undertaken was extremely limited. The literature supports the need for good staff training as central to the success of RSE programmes as it is shown to increase staff confidence and competence levels which are important factors for quality delivery of programmes.

As well as increasing the sexual knowledge base of people with intellectual disabilities through education, the literature points to the need to develop broad approaches which encompass life-skills training and personal development that help learners to

develop self-esteem and improve communication skills. Although included in some training programmes in Ireland there is no evidence from evaluative studies to indicate learning gained or indeed if this learning is transferable outside the training environment. Furthermore, from the research undertaken there appears to be a dearth of home produced training materials.

In order therefore to improve RSE provision in Ireland for individuals with an intellectual disability the following recommendations should be considered.

1. **Policies and guidelines** for RSE must be developed by all organisations in the field of intellectual disability. Such policies are critical in order to promote the delivery of standard good practice both at individual and institutional level throughout the country. Management, parents' groups, staff and service users should have input into the development of policies. Individual and service level contracts which protect rights and provides clear guidance and support to staff, need to be made available in all settings.
2. Organisations have a responsibility to provide service users with accurate and appropriate RSE. **Training** programmes must now be developed and made available to service users through all institutions in the field of intellectual disability. The literature clearly indicates the importance of balancing protection of individuals with rights to sexual expression. People with intellectual disabilities need to be recognised as sexual beings and need **supportive environments** to express their sexualities, improve their knowledge and develop appropriate sexual behaviours and relationships. Assistance needs to be provided to **parents / carers** so that they can facilitate such support.
3. The need for appropriate and adequate **training and support for staff** is a consistent theme in the literature, and is a fundamental requirement to enable them to act positively, constructively and responsibly when delivering programmes and to develop comfort and competencies in service delivery. Staff training and development is essential for the development and

maintenance of good practices. Furthermore this research has demonstrated a clear need and a willingness on behalf of staff surveyed to undertake RSE facilitation training. Thus, accredited training for those interested in delivering RSE should now be developed through universities or other tertiary level institutions, and such training should be subjected to rigorous evaluation and regular review.

4. The available evidence on the effectiveness of sexual health promotion programmes with people with intellectual disabilities is very weak, suffering from a number of methodological and design flaws. However, it is important to note that the absence of evidence of effectiveness does not equate with evidence of ineffectiveness. From the limited available evidence base of international evaluations of sexual health programmes, there is some evidence to suggest that a pragmatic approach which involves professionals (internal and specialists from outside agencies), parents and people with intellectual disabilities is potentially the most effective approach for sexual health promotion with this group.
5. The survey of practitioners working with people with intellectual disabilities in Ireland has demonstrated that respondents believe programmes should be rights based, focusing on the positive aspects of human sexuality as well as increasing knowledge, confidence and self-esteem. There is an acceptance and willingness amongst staff that sexual health needs to be promoted amongst people with intellectual disabilities. Programmes and materials need to be culturally specific and appropriate to age and ability. Thus Irish designed programmes, which suit the needs of Irish learners, must now be developed and appropriate state funding made available.
6. Greater emphasis accompanied by financial support and training must also be given to improve the quality of the evaluations for all programmes. Such action will require guidance and training on rigorous evaluation methodologies as well

at the time and resources to conduct robust evaluations to establish the effectiveness of training and sexual health promotion programmes.

7. The literature review demonstrated a general lack of research knowledge on the feelings, practices and needs of persons with intellectual disability internationally. Whilst research is underway in Northern Ireland, further Irish based research is required to ascertain the sexual knowledge, attitudes, experiences and behaviours of persons with intellectual disability. Further qualitative research is needed to explore the views and experiences of parents and staff (including teachers) who work with people with intellectual disabilities.
8. Repeal of the Criminal Law (Sexual Offences) Act (1993) and Relationship and Sexuality Education and cohesive national guidelines backed up by individual and service level contracts are essential in order to guarantee maintenance of the general health and well-being of persons with an intellectual disability in Ireland and underpin all of the above recommendations.

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Appendix 1.

Relationship and Sexuality Education Questionnaire

SECTION 1. Your Organisation

Q.1. Please indicate the type of organisation in which you work:

- Special School
- Mainstream Education
- Intellectual Disability Service
- Other (please specify) _____

Q.2. How many service users are there in your organisation?

Q.3. Please indicate the client age groups relevant to the organisation (please tick as many boxes as are appropriate):

- 17 and under
- 18-24
- 25-40
- 41-55
- 56-over

Q.4. Has the organisation developed any Relationship and Sexuality Education in-house training policies?

- Yes
- No
- Don't know

Q.5. Do you consider Relationship and Sexuality Education to be important for (please select between a. b. or c.):

a). Some of your clients (Please give reasons for your answer)

b). None of your clients (Please give reasons for your answer)

c). All of you clients (Please give reasons for your answer)

Q.6. Is any form of Relationship and Sexuality Education delivered to your client groups?

Yes

No

Q.7. If you answered Yes to question 6 is this training delivered by?

In-house trainers only

Outside agencies

A combination of both

If you answered Yes to Q.6 please go straight to Q.11.

Q.8. If you answered No to question 6 please state the reason(s) why, in your opinion, Relationship and Sexuality Education is not provided:

Q.9. What do you think your organisation requires in order to deliver Relationship and Sexuality Education?

Q.10. Would you be interested in? (please tick as appropriate)

- Receiving training in RSE facilitation
- Receiving information only
- Not interested in receiving any training or information

If you answered **NO** to question 6 please return the questionnaire in the envelope provided to:

Margaret Allen, Sexual Health Centre, 16 Peter Street, Cork.
By email to margaretallen@sexualhealthcentre.com
or fax 021-4274370 by Friday 8th April 2005.

Thank you for assisting in this study. Your information will be treated in the strictest confidence.

SECTION 2. Your Training Needs

Q.11. What percentage of your work as a facilitator is devoted to the delivery of Relationships and Sexuality education programmes?

- 1-10%
- 10-25%
- 25-50%
- Over 50%

Q.12. Have you received specific training in the theory and practice of Relationship and Sexuality Education?

- Yes
- No

Q.13. If Yes please specify type(s) and duration

Q.14. How effective would you consider this training was in enabling you to facilitate training?

(Not at all effective = 1 and very effective = 10)
Not at all effective 1 2 3 4 5 6 7 8 9 10 Very effective

Q.15. Do you have a professional qualification in the area of Relationship and Sexuality Education?

- Yes
- No

Q.16. If Yes please specify the qualification(s):

Q.17. When did you last attend Relationship and Sexuality training to update your skills?

- Never
- Less than 1 year
- 1-3 years
- 4-7 years
- Over 7 years

Q.18. Please indicate the type(s) of training received:

Q.19. Please use the following scale to indicate how comfortable you feel in delivering Relationship and Sexuality Education?

Very Uncomfortable 1 2 3 4 5 6 7 8 9 10 Very Comfortable

Q.20. Please use the following scale to indicate how competent you feel in delivering Relationship and Sexuality Education?

Not at all competent 1 2 3 4 5 6 7 8 9 10 Very Competent

Q.21. What specific training needs do you currently have in relation to Relationship and Sexuality training?

SECTION 3. Programme Delivery

Q.22. What issues/topics are covered in your Relationships and Sexuality education programmes?

(Please tick as many as are appropriate)

- Contraception
- Rights and Responsibilities
- Sexually Transmitted Infections
- Friendship skills
- Life stages
- Parenting
- Making choices
- Puberty
- Masturbation
- Body parts
- Public and Private
- Communication Skills
- Self awareness
- Confidence Building
- Reproduction
- Sexual expression
- Gay/Lesbian relationships
- Feelings and Emotions

Other (please specify) _____

Q.23. What form do the programmes take?

(Please tick as many as are appropriate)

- Individual
- Presentations
- Discussion Groups
- Question and Answer sessions
- Video
- Group work
- Art/Drama
- Ad hoc (in response to particular incidents)
- Other (please specify)

Q.24. Are your RSE Programmes?

- Ongoing
- Once off

Q.25 (a). What percentage of the total service users are in receipt of these Programmes?

- 1-10%
- 11-25%
- 26-50%
- Over 50%

Q.25 (b). Please state the age range of those in receipt of training.

- Adults
- Under18's

Q.25 (c). Please state the level of Intellectual Disability among those in receipt of training.

(Please tick as many as are appropriate).

- Mild
- Moderate
- Severe
- Profound

Q.26 Please list any training materials/manuals used to assist in delivering training:

Section 4. Your Ideas

Q.27 (a). Who do you think is most appropriate to deliver Relationship and Sexuality training? (Only tick one box)

- Frontline staff (please specify)_____
- Multi-disciplinary staff (please specify)_____
- Specific Relationship and Sexuality trainers
- Other (please specify)_____

Q.27 (b) Please give reasons for your answer:

Q.28. Do you feel the general level of relationships and sexuality education offered in Ireland to individuals with an intellectual disability is?

- Excellent
- Good
- Adequate
- Poor

Q.29 In your opinion what conditions are necessary to encourage the delivery of good Relationship and Sexuality training models?

Q.30 Please use the space below for any additional comments you wish to make:

Thank you for completing the questionnaire. We value your opinions and your information will be treated in the strictest confidence.

If you would like to be involved in a follow-up telephone interview to express your views further on the issue please fill in your details below and a researcher will contact you shortly.

Name _____

Daytime phone number _____

E.mail _____

Please return the questionnaire in the envelope provided to:

Margaret Allen, The Sexual Health Centre, 16 Peter Street, Cork.

By email to margaretallen@sexualhealthcentre.com

or fax 021-4274370 by Friday 8th April 2005.

Appendix 2.



Dear Colleague.

The Irish **Sex Education Network** (ISEN) was established to promote high professional standards and best practice in the area of sex education focused on people with disabilities.

In conjunction with the **National Disability Authority** and the **Crisis Pregnancy Agency** the ISEN are undertaking research, which will examine the current status of Relationship and Sexuality Education practice for people with an intellectual disability. The research will also make recommendations for the future development of the service in Ireland. The ISEN and myself, the researcher, would greatly appreciate it if you and your organisation would support the research by facilitating the completion of the accompanying questionnaire.

Section 1 of the questionnaire may be completed by the Director/CEO of the organisation, however sections 2, 3 and 4 should be completed by the person or persons who currently deliver Relationship and Sexuality/Personal Development programmes within the organisation.

It is important that the first section of the questionnaire is completed even if no Relationship and Sexuality training programmes are delivered in your organisation, as the information provided is valuable to the study.

Please distribute photocopies of this questionnaire to all appropriate colleagues for their completion. The reference number on questionnaires does not identify an individual service.

If you would like to receive information about the Irish Sex Education Network please contact the Chairperson Ms Fiona Coffey on 087-6284538 or by email isentraining@yahoo.co.uk.

If you have any specific queries about the completion of the questionnaire or about the research project, please, feel free to contact me at margaretallen@sexualhealthcentre.com or phone 021-4275837.

May we take this opportunity to thank you in advance for your participation in this study. We value your opinions and the information given will be treated in the strictest confidence.

Yours sincerely.

Margaret Allen

Researcher on behalf of the ISEN.