



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

friendships and taboos

Research on Sexual Health
Promotion for People with Mild
to Moderate Intellectual Disabilities
in the 18-25 Age Range

**RESULTS OF A CONSULTATION PROCESS
AND LITERATURE REVIEW**

Foreword	2
Acknowledgements	3
About the authors	4
1.0 Introduction	5
1.1 What was the purpose of the research?	5
1.2 Overview of methodology	5
1.3 Definitions	6
2.0 Summary of main themes from literature review	7
2.1 Policy developments	7
2.1.1 International and national policy developments	7
2.1.2 Development of policies within organisations at a national level	8
2.1.3 Implications for policy and practice	8
2.2 Attitudes towards the sexuality of people with intellectual disability	9
2.2.1 Historical and societal perspectives	9
2.2.2 Parents	9
2.2.3 Implications for policy and practice	10
2.3 Sexual knowledge, attitudes, behaviours and aspirations of people with intellectual disabilities	10
2.3.2 Sexual health of people with intellectual disabilities	11
2.3.3 Sexual health promotion for persons with an intellectual disability	12
2.3.4 Implications for policy and practice	13
2.4 Final conclusions	13
3.0 Summary of main themes emerging from the research project	15
3.1 Summary of needs identified by respondents within the consultations	15
3.1.1 Summary of perceived needs of service users	15
3.1.2 Summary of needs of staff	17
3.1.3 Staff training needs	17
3.1.4 Materials and resource needs	18
3.1.5 Staff perspectives on parents needs	18
4.0 Discussion on common themes	20
4.1 Sexual health for persons with an intellectual disability is a rights issue	20
4.2 Capacity and legal uncertainties on capacity to consent	20
4.3 Development of policies at a national level	21
4.4 Development of policies at an organisational level	21
4.5 Consultation with service users and parents	22
4.6 Training and development of standards for RSE delivery	23
4.7 Materials and resources / Short term – immediate ideas / Medium term ideas / Longer term ideas	24
4.8 Facilitation of networking	25
4.9 Advocacy within senior management regarding the importance and relevance of this work	25
4.10 Research and progressing research	26
5.0 Final conclusion	26
Appendices	27
Final note	38
Bibliography	39

Foreword

Sexuality and disability is an area which historically, has been widely overlooked or else cast in a somewhat negative light. When there has been a focus on sexuality and disability, it has tended towards the problematic, i.e. viewing a disabled person's sexuality as a problem which needs to be solved, rather than looking at their right and need for sexual expression. In recent times there has been somewhat of a shift towards the acknowledgement of clients needs in this area. As a result, a number of policy documents and legislative reviews have recently taken place. At a more local level, many disability organisations are not only seeking to implement policies both to protect and support staff and clients, they are also proactively working on providing their clients with training and information on sexual health and relationships.

The target group selected in this proposal has been identified as many interventions which focus on young people tend to exclude the experiences of those with an intellectual disability. As it currently stands, there is no specific Relationship and Sexuality Education programme for young people with an intellectual disability within the Irish school system. In the absence of such a programme people with intellectual disabilities are often solely dependent on disability organisations and parents to fill this information void. Parents and organisations often struggle with the dilemma of championing the sexual rights of people with intellectual disability while ensuring that the vulnerable are protected.

Sexuality and Disability is indeed a complex and often challenging subject and it is an area where there is much for us to learn as societal attitudes develop and change.

There is much work to be done in this area and this report seeks to highlight these issues, concerns and areas for future development in this field.

Health is influenced either positively or negatively by a variety of factors. The social determinants of health (including issues such as lack of education and discrimination) all contribute to health inequalities. Population Health views addressing Health Inequalities as one of its key priorities. In commissioning this report Population Health believes that by providing a National and International overview, this report will serve to ensure that future work in this area is couched within best practice and it may also serve to ensure that the sexual health rights of those with an intellectual disability is kept firmly on the agenda.

The HSE looks forward to working with partners in the statutory and voluntary sector to promote the health of those with an intellectual disability.

Cathérine Murphy

Assistant National Director of Population Health / Health Promotion



Acknowledgements

I would like to thank all those who have been involved with this research over the past three years. I would like to especially thank the individuals and agencies within the Disability Sector who gave their time, shared their experiences and offered their professional expertise. This sharing ensured the report would represent the excellent work being done within this sector and to identify areas where health professionals need to focus in the future.

The list of all those involved is extensive, and I would draw the reader's attention to the appendices for a detailed list of the people and agencies involved in the consultation process.

The subject of intellectual disability is broad and complex; combined with sexual health promotion the subject of Intellectual Disability raises diverse opinions and experiences. To this end, I would like to thank Ms. Sharon Foley of One2One Solutions for the dedication and professionalism demonstrated in researching and compiling this report. Also, to Ms. Grace Kelly research student who co-authored the Literature Review.

This research would not have been possible without the necessary funding and support given by SPRI (Strategic Planning and Reform Implementation).

Finally, this report is indebted to the Health Promotion Sexual Health team for driving the project on, in particular project leaders, Ms. Sharon Parkinson, Senior Health Promotion Officer, Ms. Catherine Byrne, Health Promotion Officer and Mr. Martin Grogan, Health Promotion Officer for his support in bringing the report to print.

Mr. Andy Walker

*A/Functional Manager
Health Promotion Department, HSE South*



About the Authors



Sharon Foley, MA, MSc

Sharon has worked as CEO of the national Crisis Pregnancy Agency and as Regional Health Promotion Director in the health services. Previous experience involved working with socially excluded groups, county development boards and community based partnerships, delivering education and training, commissioning and evaluating research projects and facilitating groups. She also worked within the Department of Health and Children as a senior nutritionist. In 2006 she established her own consultancy business providing research, evaluation and strategic planning services to clients in the public and voluntary sector. Sharon holds a BSc in nutrition, an MA in health promotion, an MSc in research and a certificate in change management.



Grace Kelly

Grace Kelly completed the literature review for this project. Grace is currently in the final year of a PhD on “Sexual Rights and Learning Disability” where she has carried out focus groups with people with mild and moderate intellectual disabilities, their family members and staff. Grace’s research is funded by the National Disability Authority and the Central Remedial Clinic. Grace is a long term member of the Irish Sex Education Network and was part of a team overseeing ISEN research on “The Current Status of Sex Education Practice for People with a Learning Disability in Ireland”. Grace has recently been collecting the life stories of older people with intellectual disabilities in Ireland.

Authors’ Acknowledgements

The author would like to extend thanks to all staff and their management in the intellectual disability services for their time in attending consultations and providing information to the study, and all the experts who gave of their time to be interviewed.

Finally, I would like to thank the HSE for commissioning this work and in particular the steering group of the SPRI team, Sharon Parkinson and Catherine Byrne, who provided ongoing support throughout the project.

Sharon Foley, July 2009

1.0 Introduction

This research project was commissioned by the HSE in 2006. The results are intended to inform and underpin any future training / support in sexual health promotion that will be provided for people with mild to moderate intellectual disabilities ranging in age from 18 – 25. The research was carried out under the auspices of the Strategic Planning and Reform Implementation team (SPRI) and HSE health promotion / population health functions. The original work was completed in early 2007 but in 2009 the HSE looked to have it updated and made available to a wider audience. The update was completed in early 2009.

This summary document was prepared by Sharon Foley. The synopsis of the main themes emerging from the research project is based on a fuller report available from the HSE. The summary of the literature review is based on a fuller literature review completed by Sharon Foley and Grace Kelly, a PhD student specializing in the area of intellectual disability and sexual health.

1.1 What was the purpose of the research?

As stated already the Health Service Executive (HSE) commissioned this research to inform and underpin any future training / support in sexual health promotion that will be provided for people with mild to moderate intellectual disabilities ranging in age from 18 – 25. The primary goal of the research was to engage with service providers at a staff and management level.

The research aimed to create a better understanding of the needs in the area. To this end the specific outcomes envisaged by the research team included;

- A literature review and a review of national and international best practice in terms of sexual health promotion and intellectual disability.
- A national review of disability services with service users focusing on the current provision of sexual health promotion.

- A needs assessment - focusing on staff, service users and parents / care givers.

The specific project objectives were;

- To produce a research document that outlines current national and international promising practice in sexual health promotion for people with mild to moderate intellectual disabilities.
- To clearly establish the types of work (if any) currently being carried out by the disability organisations in relation to the sexual health promotion of people with mild to moderate intellectual disabilities.
- To devise and produce a needs assessment that clearly outlines the supports, training and information required by service users, staff, parents and carers when addressing the issues of sexual health and intellectual disability.

1.2 Overview of methodology

The research study sought to explore the experiences and needs of those working in the field of intellectual disability using the following methodologies;

- A literature review. This was completed by Grace Kelly, PhD student working with Sharon Foley. This literature review was completed in 2007. Small updates were made in 2009 (see appendix 1). The review is available from the HSE.
- An initial questionnaire to service providers that would deliver an overview of developments.
- A series of qualitative focus groups with service staff and people with responsibility for policy development and management within the services.
- A number of workshops with service providers from the HSE, with sexual health service providers, with the Irish Sex Education Network (ISEN) and the National Learning Network (NLN).
- A number of one-to-one interviews with persons considered to have a particular expertise in this area (see appendices 2,3 & 4).

In total nine workshops / focus groups were held around the country. Of these;

- Four were held specifically for staff working within the services for intellectual disability.
- One was organised for those with responsibility around policy development and management within the services.
- One was for sexual health service providers.
- One was convened for HSE staff working either in the field of disability or sexual health / health promotion.
- A meeting was held with members of the National Learning Network.
- A workshop was held with the Irish ISEN members.

Forty two voluntary service providers were initially contacted in relation to the research. Additional contacts were issued to services in Cork (based on HSE information) and NLN Centres. Of these, 31 services either attended a workshop or returned a questionnaire.

1.3 Definitions

Within the literature review, intellectual disability is defined as a condition of arrested or incomplete development of the mind which is especially characterised by the impairment of skills manifested during the development period, which contributes to the overall level of intelligence i.e. “cognitive language motor and social abilities”. In Ireland the prevalence of intellectual disability is 2.26 per 1000 for mild intellectual disability and 2.43 per 1000 for moderate disability. These figures are sourced from the National Intellectual Disability data base but it must be pointed out that persons with mild or borderline intellectual disability who are not receiving services are not represented on this data base. The Physiological Society of Ireland estimates that a more accurate prevalence of mild intellectual disability is likely to be 8 per 1000.

2.0 Summary of main themes from literature review

Completed by Grace Kelly, PhD student and Sharon Foley

Sexuality and sexual health promotion for persons with a mild to moderate intellectual disability is a complex and evolving issue. The literature review sought to capture the emerging trends around theoretical approaches, policy development, and trends in health service delivery. It also sought to provide an insight into current research on knowledge, attitudes and behaviours amongst staff, parents and service users.

Intellectual disability services are provided in the main by voluntary organisations. Almost 16,000 people attend day programmes operated by these organisations of which 43% have a mild level of intellectual disability and 47% are aged 18 years or under. In comparison, full time residential services are used by nearly 8,000 people of whom less than 20% have a mild intellectual disability.

Over the past decades there have been major changes in how services are delivered. Current services are based on the principle of normalisation with a clear focus on ensuring persons with intellectual disability have as normal a life as possible.

Various definitions of sexuality, sexual health and sexual health promotion are provided in the literature. The World Health Organisation (WHO) operates out of a working definition of sexual health that reads as follows: *“A state of physical, emotional, mental and social wellbeing related to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sex experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled”*. (WHO 2004)

All work in the area of sexuality and sexual health acknowledges that there are wide influences on sexual health including economic, societal, political and educational influences.

2.1 Policy developments

2.1.1 International and national policy developments

Internationally there have been a number of developments that seek to protect and ensure the rights of persons with intellectual disability. The most recent development was the publication of the *United Nations Convention on the Rights of Persons with Disability* in 2006. This document states that for persons with a disability there should be respect for home and family and it specifically enshrines the right to be allowed to marry and have children. This was ratified by the Irish Government in March 2007 and an interdepartmental task force is at present examining the Irish legal system to ascertain where the current legal framework in the Republic of Ireland (ROI) will need to change to accommodate the requirements of the UN convention.

Of continued relevance to services is the *UN Standard Rules for the Equalisation of Opportunities for Persons with Disabilities* which specifically examines the concept of sexuality and the rights for persons with a disability to explore their sexuality.

These international documents open up the concept of sexual health as a right. While there is widespread agreement that in principle people with intellectual disabilities have the right to sexual expression, there is much uncertainty concerning the exact nature of such a right. These rights are not protected within the national or organisational policies governing the care of people with disabilities and to be meaningful the concept of rights needs to be embedded in the policies and procedures of organisations.

In summary, there is strong international consensus to support the development of rights-based policies and approaches leading to the realisation of positive sexual health for persons with an intellectual disability.

Within the Irish context the National Disability Act 2004 establishes a system for the assessment for individual health service and educational needs. However there is no statutory requirement to provide all the services identified although government departments are required to prepare sectoral plans to indicate how they are implementing the strategy. In 2008, the Health Information and Quality Authority (HIQA) produced its draft National Standards for Residential Disability Services. While these standards are in draft at present they do outline the supporting criteria against which services will be measured.

As part of the debate concerning intellectual disability and sexual health the concept of capacity to consent is crucial. A core question arises as to whether a person with an intellectual disability has the capacity to consent to relationships and in particular sexual intercourse. In Ireland this is further complicated by the Criminal Law Sexual Offences Act, 1993, which states that it is a criminal offence '*to have or attempt to have sexual intercourse with a mentally impaired person or to attempt to commit buggery with a mentally impaired person (other than a person to whom you are married)*'. The act has resulted in a lot of confusion within disability services as to whether carers who facilitate a sexual relationship between service users are guilty of aiding and abetting the commission of a criminal act and creates uncertainty regarding the status of policies and programmes.

In 2005, the Law Reform Commission (LRC) produced a Consultation Paper on vulnerable adults and the law in relation to capacity (LRC CP37-2005). As part of this the paper explored the whole notion of capacity to consent to sexual relationships. Their work has resulted in the publication of the Mental Capacity Bill which provides clearer direction around the issue of capacity for vulnerable adults. However, as recommended by the LRC, this bill specifically excludes any consideration in relation to capacity to sexual relationships. The commission felt at the time that this was a very complex area and required a programme of work in its own right. As such the areas of capacity to consent to sexual relations for persons with an intellectual disability will be examined in due course by the LRC in the context of their third programme of work. At present, this

means that the 1993 Criminal Act remains valid and service providers must abide by its direction. From a practical perspective this clearly creates a dilemma for many providers.

The available research literature acknowledges that it is very difficult to measure capacity to consent and existing methodologies and criteria are poor. International literature in the area indicates that underlying assumptions can influence the outcomes of measures to determine capacity and attempts to provide an objective evaluation of capacity to consent to sexual expression can lead to different outcomes. Recent Irish research completed by Evans (2002) shows the need for methodologies, criteria and clear guidelines to assist staff in establishing the type of relationship a person is capable of where relationships are consensual.

2.1.2 Development of policies within organisations at a national level

Many authors argue that there is a need for strong policy at an organisational level so that clients know their rights and responsibilities, that parents are aware what practices are permitted and staff are aware of their professional obligations. Moreover the process of developing a policy provides an opportunity for an organisation to fully explore this complex area. Many organisations have developed organisational policies to look at sexual health and intellectual disability. However there is no national driver to develop policies and the motivation for policy development rests with individual organisations. The literature review examines what constitutes good organisational policy. In addition to the international evidence supporting the need for a rights-based approach, good organisational policy should spell out an agency's position on a variety of sexual issues and put boundaries around staff behaviour. Policies should be relevant, meaningful and helpful to clients; they should give clear direction to care employees and must be supported by training and review.

Many authors have argued that the process surrounding the development of policy is just as important as the policy itself. Those with experience in developing policies recommend the adoption of a consultative approach that

incorporates the views and opinions of service users, parents, staff and management. There are considerable resource implications in developing good policy as time needs to be allocated to facilitate proper consultation.

2.1.3 Implications for policy and practice

The literature review provides strong support for the development of rights based policies at organisational and national level. In essence the international agreements, of which Ireland has been a part, provide the starting points from which to develop good policies. The research to date strongly supports the development of policies both at a national and more specifically at an organisational level. There is clear guidance and examples upon which to develop good policies but the literature has also captured some of the difficulties around policy development such as the need to dedicate sufficient resources and time to ensure proper consultation and meaningful engagement with service users and their families.

Finally, once legal issues in relation to capacity are progressed, service providers will require robust and simple tools to measure capacity.

2.2 Attitudes towards the sexuality of people with intellectual disability

This section of the literature review examines some of the historical developments around sexuality and intellectual disability and looks at current research around the attitudes of staff and parents.

2.2.1 Historical and societal perspectives

Historically the sexuality of persons with intellectual disability was seen as problematic for families and the staff charged with the management of disabled persons. In the past policy and practice in the area was informed by the approach of the Eugenics Movement, a policy that resulted in many persons with intellectual disability being sterilised without their consent. This practice began to be challenged in the late 20th Century and is rarely practised today. Current research indicates that societal attitudes towards the sexuality of people with intellectual

disability can be positive with many people accepting that persons with intellectual disabilities are entitled to much the same opportunities as everyone else. However there is still evidence of 'mixed feelings' in this regard primarily centring on the notion of capacity. For example in a Special Olympics survey undertaken in 2003, 53% of Irish respondents thought that people with intellectual disabilities were capable of marriage but only 23% believed they could raise children.

Other research has shown huge variances between the values and attitudes of staff around the sexuality of persons with intellectual disability. The opinions of staff members are crucial in any work around intellectual disability as they have a powerful role in the lives of their clients. A key finding has been that although staff may have positive attitudes towards the sexuality of persons with intellectual disability this does not always influence their willingness to provide sex education. Many staff are reluctant to provide sufficient sex education for fear of reprisal from parents or the organisation and concerns around capacity of the individual.

In some of the papers reviewed people engaged in mainstream sexual health provision reported feeling uncomfortable and fearful of working on issues of sexuality with persons with intellectual disability and their families. For many this stems from their sense of the vulnerability of persons with intellectual disability and the risk of their being sexually abused. Studies to date highlight the need for disability awareness training for sexual health professions.

2.2.2 Parents

For the most part parents are the primary carers for persons with intellectual disability. The research indicates that sexuality is a major issue for parents of children with intellectual disability; their concerns generally revolve around possible exploitation, inappropriate behaviour and a fear of pregnancy. Some research reports that such parents are more likely than parents of non-disabled children to be resistant to their child's sexuality believing that their children are permanent children and thus asexual. In Evans (2002) study the parents interviewed did not believe that the person they cared for was capable of intimate relationships. However other recent research has shown that parents primarily want their son or daughter to be happy, not to be

lonely and to have someone special. Their primary concern is the protection of their son or daughter. Researchers argue that organisations for people with intellectual disabilities have a role to play in informing and educating parents or carers.

2.2.3 Implications for policy and practice

The current research on the attitudes of staff appears to show that there may be variances in the attitudes of staff at an organisational level. This points to the need for standardised training to ensure that the values and attitudes of staff do not influence the provision of relationship and sexuality education and the guidance provided to service users.

The research also shows the need for greater engagement with staff members least likely to volunteer for training courses. In addition more time could be dedicated to exploring staff attitudes and values in the course of regular training.

It is clear from the research that parents have real concerns about the sexuality of their children. Any work completed within organisations around this area must include and involve parents and recognise that parents may need support and assistance in coming to terms with and supporting their son's or daughter's sexuality.

2.3 Sexual knowledge, attitudes, behaviours and aspirations of people with intellectual disabilities

The literature shows that sexual development for people with mild and moderate intellectual disabilities is by in-large normal and similar to that of the general population.

2.3.1 Sexual health knowledge

The sexual development for people with mild and moderate intellectual disabilities is by in-large normal and similar to that of the general population. However the literature shows that people with intellectual disabilities are rarely allowed to express their sexuality in a normal healthy manner unless they are living in respectful and supportive environments.

The literature review outlines in detail available Irish research exploring the attitudes, knowledge and experiences of persons with intellectual disability. In general, persons with an intellectual disability show low levels of knowledge and awareness around all matters of sexual health, body awareness, contraception and relationships. The literature shows that while some people have some understanding of sexual intercourse there remains a lot of misunderstanding as to the actual mechanics of sexual intercourse and pregnancy. There is a clear warning in some of the literature that a lack of knowledge about pregnancy could result in people engaging in sexual intercourse without understanding the possible consequences.

On the whole the attitudes of people with intellectual disabilities towards masturbation appear to be conservative or negative and illustrates guilt and stigma surrounding this behaviour on their part.

These low levels of knowledge and awareness contrast starkly with the desires and aspirations of persons with intellectual disabilities to form relationships. In all research, participants report a strong desire for intimate relationships. Available research shows that many people with intellectual disabilities do engage in sexual activity. In one Irish study participants had positive attitudes towards sexual intercourse even though the majority knew little about contraception and were unlikely to engage in intercourse. The research shows that persons with intellectual disability are often confused about the appropriateness of certain behaviours and lack accurate knowledge and about appropriate sexual behaviours.

In relation to marriage and the creation of a family much of the research shows that many persons with intellectual disability do not believe that either will happen for them. Many have a desire to get married but that many have a limited understanding of what people do when married.

Throughout the research many barriers around safe sexual expression are identified. Some of these relate to misinformation. This includes information which may be withheld from persons of intellectual disability because of a belief that such information is not relevant or alternatively they may be provided with misinformation in order to curb certain

behaviours e.g. masturbating. Misinformation has implications for persons with intellectual disability as they may engage in behaviours without fully understanding the consequences for themselves or others. The research indicates a need to provide accurate information to people with intellectual disabilities and also a need to provide information for parents and staff.

The Irish research available shows that people with intellectual disabilities are likely to face negative attitudes from their peers and families. This has implications as people may not know how to express their sexuality or may feel limited in asking others for help and information. As a protective mechanism, families may over protect the disabled person with the result that people with intellectual disabilities rarely have the opportunities to meet others.

Finally disability services themselves can act as a barrier to the formation of relationships. Loneliness is a key factor in the lives of many persons with intellectual disability. The research highlights a recurring theme that persons with intellectual disability are limited in their opportunities to form relationships and many view the services as their key social outlet.

The research shows that services themselves can act as a barrier to the formation of relationships either through supervision or rules about behaviours. The research recommends that services may have to develop skills and abilities in enabling their clients to form relationships of all kinds. Many of those availing of their services may have limited opportunities to develop such relationships in other settings.

In conclusion, it is clear that persons with intellectual disability do not have sufficient levels of knowledge regarding sexual health. This could be damaging to their future health and well-being and does not correspond to their desires to form relationships or to their level of sexual experimentation and activity.

2.3.2 Sexual health of people with intellectual disabilities

The research to date shows that the sexual health of people with intellectual disabilities is an area which has been poorly researched and requires more systematic and focused research. It is clear that best practices for providing sexual health services will be limited in their establishment if there is not sufficient evidence from quality research. The available research, albeit limited, is quite revealing.

Self-esteem and self-image are important components of positive sexual health. However much of the research shows that persons with intellectual disability often do not see themselves as adults even if they show the sexual preferences of adults. This emphasises the need for people with intellectual disabilities to be given clear and factual information regarding their sexuality in order for them to be able to behave as responsible adults when engaging in interpersonal relationships.

In relation to menstruation Irish studies have highlighted that many women with intellectual disabilities have difficulties managing the symptoms of menstruation and this can be sited as a 'difficult to manage' issue for staff. However other research has shown that education and supports are effective in supporting and educating service users around their menstrual self care. In relation to the menopause, the limited research available shows that there is a considerable lack of knowledge around the menopause for women and this can be a cause of increased stress for women at this time of their lives.

The research is particularly limited in relation to contraception and the use of contraceptive services. It is clear that this is an area which has been overshadowed by debates about reproductive freedom and the rights of women with intellectual disability to reproduce. It is a highly sensitive debate and one which has not been fully explored within an Irish context. The available research shows that sexually active persons with intellectual disability have a desire to receive more information around contraception. There is a clear need to reconcile the levels of sexual activity with skills and knowledge to protect sexually active persons from unwanted pregnancies and to exercise

reproductive choices. There is no Irish information on the fertility rates of persons with intellectual disability or on sterilization.

In relation to STIs and HIV / AIDs the research shows the persons with intellectual disabilities engaging in sexual activity are at high risk of STIs as they are less likely to receive general education and information to ensure safer sex. In addition they often have limited access to affordable care should they become HIV positive. This is an area, which may become a greater concern as the experience of hetero and homosexuality among persons with intellectual disability is often hidden. In relation to homosexuality, the fact that many educational resources do not properly explore and define the area is a further limitation.

The issue of sexual abuse is heavily debated within the research literature with some researchers feeling that there is an over emphasis on this to the detriment of all other aspects of sexual health. The most powerful Irish study was that completed by McCormick *et al.*, (2005) which showed that sexual abuse is a reality within services. In their study almost half of 250 allegations of sexual abuse examined were confirmed. More than half of the perpetrators were adolescents and adults with intellectual disabilities. A frightening finding among this research was the level (about 10%) of people with intellectual disabilities who thought it was appropriate to engage in intimate touching with family members or strangers. The results within the literature clearly illustrate a need to ensure that persons with intellectual disability are protected through knowledge and skills, with clear organisational policies and guidelines against potential sexual abuse.

The literature review briefly explores gender issues and shows that women with intellectual disabilities experience more restrictions and controls in their social and personal environment than do men of similar ability levels. However it must be noted that literature is very limited in this regard. In particular the literature around men is very limited and primarily focuses on deviant sexual behaviour of men. The literature also shows that female staff members are much more likely to attend training courses around relationships and sexuality. This may mean that boys and men are receiving

education from male care givers who are not well informed and up to date with the issues or that it is primarily their female care givers who provide this information.

2.3.3 Sexual health promotion for persons with an intellectual disability

Curriculum guides on Social Personal and Health Education (SPHE) for mild, moderate and severe intellectual disability have been developed by the National Council on Curriculum and Assessment (NCCA). However, there is no national relationships and sexuality programme adapted to the needs of people with intellectual disabilities outside of mainstream education.

A recent study in 2006 from the Irish Sex Education Network (ISEN) shows that the majority of people under and over 18 with intellectual disabilities receive little sex education. This is despite evidence of a strong rationale (see appendix 1) showing that the provision of accurate knowledge and information to persons with intellectual disabilities is a mechanism to protect them from exploitation and unwittingly offending others.

Sexual health promotion programmes described in the literature have been implemented to achieve a wide range of objectives. Such programmes have usually included individuals with mild to moderate intellectual disability working in groups in relatively short sessions over a period of several weeks.

The aims of the programmes included improving social skills as they relate to various levels and degrees of personal interaction. Programmes are also designed to improve knowledge of the facts about sexuality and to teach abuse prevention tactics. They are also designed to provide information about specific issues such as how to manage menstruation or to avoid STIs. Commentators have noted that most programmes do not seek to improve attitudes towards sexuality. In addition many commentators criticise programmes for being too focused on biological functions. The literature review examines briefly some of the considerations around providing relationships and sexual health education. Such considerations include timing, the importance of choosing and adapting curriculum and assessing needs before the programme commences.

A key weakness identified in the literature is the lack of evaluated programmes. Indeed there does not appear to be any evaluation frameworks available for programmes. The absence of evaluation means that learnings and lessons from previous work and experience are not available within the research literature. There is a clear need to develop evaluation frameworks for sexual health promotion programmes for people with an intellectual disability.

There is some research available which shows that training provided to staff working with persons with intellectual disability can be effective in improving attitudes and values about the rights of persons with a learning disability around issues of sexuality. Staff who have taken training courses are often more open to adult clients' expression of sexuality and to clients having children. However this is an area which requires further research. In addition there is very little research available, particularly in the Irish context, concerning the levels of training of sexuality educators.

2.3.4 Implications for policy and practice

The available research shows that persons with intellectual disabilities have both aspirations to form relationships and experience in both sexual and non-sexual relationships. This contrasts with the poor level of knowledge shown in research regarding all matters of relationships and sexual health. Clearly there is a gap identified through this literature review, which shows that if persons with intellectual disability are to be adequately protected by those who care for them then they must be provided with the information and skills around relationships and sexuality. This has implications for the development of programmes and also further illustrates the need for policies and mandates to support the development of relationships and sexuality education within care services.

There is a need to develop evaluation tools and frameworks and a need to encourage the completion of research projects and ensure the publication of these in peer journals.

Good practice indicates that in developing programmes a significant amount of time should be spent in adapting and testing approaches. These considerations have resource implications for

organisations if only in relation to the time that must be devoted to planning and monitoring programmes.

2.4 Final conclusions

The major themes that emerge in the literature are as follows:

- There is little policy within the area of sexuality and health promotion for persons with an intellectual disability and there are major legal barriers to the development of policy within an Irish context. In comparison, strong policy does exist around the area of protection against sexual abuse.
- This lack of policy has implications. At the very least many persons with an intellectual disability are being denied a basic human right to form relationships. Contemporary policy is moving towards an emphasis on rights and the promotion of sexual health.
- The sexuality of persons with intellectual disability is more often considered as a problem than as a normal human condition by parents, caregivers, and the general public.
- There is comparatively less knowledge about the sexual needs of persons with intellectual disabilities and about their intimate relationships compared to the general population.
- Individuals with intellectual disabilities seem to have little knowledge about sexual matters and little opportunity to make personal decisions and choices about intimate relationships. On the other hand, they have the same aspirations towards relationships as the general population. Their lack of knowledge places them at particular risk of sexual abuse, unhealthy relationships and poorer mental health.
- One of the challenges for services working with people with intellectual disabilities is how to meet the twin objectives of sexual empowerment and protection. Keywood (2003) comments: "Where choices have been available between facilitating the sexuality of people with learning disabilities and protecting them from unwanted sexual encounters, services have typically sought to prioritise protection over empowerment".

In summary the research shows that a number of key areas will need to be developed:

- Political will is needed to ensure that national agencies are aware of their responsibilities to develop and drive national policy and ensure the provision of relationships and sexuality education within care settings.
- Guidance and tools are needed to create positive rights-based policies within organisations.
- Programmes of training for staff working in care settings need to be developed to ensure they are comfortable and equipped to provide relationships and sexuality education.
- Programmes of training for service users are needed to be delivered within or outside of care settings.
- Programmes are needed to ensure that staff working within specific sexual health services are aware of the needs of persons with intellectual disability.
- There is a need for the development of evaluation frameworks to ensure that work in this area can be evaluated appropriately and that learning can be shared with other organisations.
- Further research is needed around many of the issues identified within the available literature as issues that require further exploration.

3.0 Summary of main themes emerging from the research project

The findings from both the expert level consultation and the staff and management consultation raise many issues with a number of recurring themes and perspectives. These are described in detail within the relevant chapters but a summary is provided below.

Overall the findings of the consultation reflect the observations made within the literature review – there is little formal Relationship and Sex Education (RSE) delivery within the intellectual disability setting though pockets of good practice appear at intervals within the services.

Overall the level of implementation appears low and many staff report that there is little sustained implementation within their service. Yet the topic of RSE arises in the context of service delivery almost on a daily basis. Staff members feel unsupported around this role and unsure of their responsibilities in relation to the delivery of RSE. All the services acknowledged that people with intellectual disabilities have a right to relationships and expression of their sexuality. They acknowledge that this is bound up with their concerns around capacity and protection of the individual against abuse.

This chapter seeks to draw together common themes and conclusions and generate a series of recommendations towards better practice in the area of intellectual disability and sexual health.

The recommendations draw on the author's experience to date around health promotion and strategic facilitation and reflect an objective viewpoint on practical and tactical next steps for the HSE to consider.

3.1 Summary of needs identified by respondents within the consultations

Staff consulted in the course of this research strongly identified with the issue of RSE and noted that relationships and sexuality arise as an issue for their clients;

- Through individual action plans / person centred plans / personal outcome measures.
- Where relationships develop between service users or between service users and those outside the agency.
- When an 'incident' of a sexual nature occurs within the care setting (often perceived as challenging behaviour).
- When trying to teach service users the differences between public versus private places.
- As a result of incidents of potentially abusive behaviour.
- As a consequence of questions from service users.
- Where relationships and sexuality as an issue coming from self-advocacy groups.

3.1.1 Summary of perceived needs of service users

Respondents at the consultations noted that the needs and aspirations of persons with intellectual disability around relationships and sexuality are no different to the general population. Having a boyfriend or girlfriend is often a measure of status among persons with intellectual disability. It is often a topic of conversation within groups and heightens the needs and desires to have a relationship. Respondents noted the need for service users to have access to services, accurate and tailored information and supportive relationships and sexuality programmes. All respondents noted the need for social outlets and active supports to enable persons with an intellectual disability make and retain friends and relationships.

Staff within consultations noted the need for ongoing consistent relationship and sexuality education programmes. There was strong agreement that people with intellectual disabilities were at risk of abuse or unhealthy sexual expression

through a lack of knowledge and skills around relationships and sexuality. They noted that there were often factors which made the needs of the persons with an intellectual disability more complex as well as a range of factors that prevented them realising their true aspirations. These included;

- Isolation: Lack of social opportunities and isolation are key aspects of the lives of people with intellectual disability. This means that there are few opportunities to create and maintain relationships. All respondents noted the need for social outlets and active supports to enable persons with an intellectual disability to make and retain friends and relationships. Respondents frequently referred to the '9-to-5' life of service users where they meet others in their interaction with services but go home to isolated lives. What might be seen as inappropriate behaviour within the public care setting in services might be the services user's only opportunity for sexual expression.
- Low self esteem among persons with an intellectual disability: This is further damaged by real experiences of rejection and ridicule from non-disabled persons. Personal awareness and body image is often poorly developed.
- Limited social skills: Service users often have limited or low understanding of social skills and less ability around being able to judge social situations– 'the nuances of what is appropriate can be hard to teach' and very little control or experience of control around making their own decisions - 'they are weaker around being an agent of power in their own lives'.
- Varying levels of realistic expectations: Some service users took their cue from siblings and TV as to what their aspirations for relationships should be, whereas others were very clear that they would have limited opportunities to have relationships.
- Guilt as an aspect of self-awareness: For many years persons with intellectual disability have been told that sex was bad and would not be part of their lives. This guilt needs to be explored in subsequent relationships and education work.
- The intellectual disability itself: This is an impact on the needs and aspirations e.g. those on the autistic spectrum may have different needs

around relationships. Those with Down Syndrome may be very trusting in their relationships. In looking at the needs of service users the impact of their disability becomes more apparent. For example, for those with mild intellectual disability, the discussion may centre on relationships and sexuality in general. For those with moderate intellectual disability it may become more important to distinguish between private and public behaviour, e.g. masturbation in public and might require more capacity building around this issue at the onset.

- Over protection: The lack of a right to the "dignity of risk" (not being allowed to try out new experiences and learn from mistakes) was raised by self advocacy groups. One agency reported that the service users say 'We have to be allowed to make our own mistakes and learn from our mistakes'.

Staff felt that 18 years was too late to begin work and that support around relationships is needed from an earlier age. A number of themes for consideration were mentioned by those interviewed. Broadly these can be summarized as follows;

- The context of service delivery to persons with an intellectual disability is changing with the trends towards increasing independence and self advocacy.
- Sexual Health Promotion is required across the life cycle, especially for younger years.
- There are specific needs within the school setting to ensure children with intellectual disability are not excluded from RSE and from support around their emotional development.
- There is little information on the impact specific disabilities have on needs around relationships and sexuality.
- There is a strong need to reach those not in disability services – these include persons with mild or borderline disability but not registered on the intellectual disability data base.
- There are real and significant risks of abuse or unhealthy expression of sexuality for persons with mild to moderate intellectual disability. Absence of information and supports can further exacerbate these risks.

When asked who should deliver RSE within the care setting the balance of opinion was that a mixture of front line staff supported by others more specialized in their area was the ideal. It was felt that it is vitally important that the staff member is comfortable on how to impart information and is aware of boundaries around this role. It was also seen as important that RSE is not delivered as a once off programme but can be repeated as often as is required.

It was a strongly held opinion that all staff must be familiar with the policies of the agency and be able to refer questions and issues to specific services or educators within the service.

3.1.2 Summary of needs of staff

There was a great deal of consistency between all groups of respondents on the key needs of staff. There were concurring responses from those interviewed that there is a real need for staff to feel comfortable about providing relationships and sexuality education to persons with an intellectual disability. In order to achieve growth and development, respondents felt this training cannot be addressed in a punitive directive manner; staff need the space to explore their own values and attitudes where they will not be criticised or judged. The key issues for staff identified within the consultations were;

- A lack of policy at a national and organisational level.
- A requirement for adequate training.
- Lack of resources and teaching materials and a lack of knowledge on available resources.
- Lack of guidelines on what constitutes proper relationships and sexuality education.
- Discomfort among staff in dealing with RSE.
- Tools and guidance to determine capacity among clients.
- Effective tools and responses to addressing the concerns of the parents.
- Tools and skills to manage challenging behaviour of a sexual nature.
- Deciding how relationships can be facilitated and/or controlled in residential settings.

The key issues identified by staff as being important for their agencies included;

- A lack of national and organisational policy and procedures.
- Current capacity legislation.
- Advocacy for service users and the issues advocacy movements raise.
- Creating social environments for service users.
- The risks around litigation and risk management.
- The challenge to provide RSE throughout care settings at all stages.
- A lack of coherence and continuity between services.
- A challenge for organisations on how to provide private spaces and how to respect privacy.

3.1.3 Staff training needs

A major recommendation coming from staff was the need for staff training – they provided recommendations on how training could be delivered at a number of levels. There was no clear sense of the competencies required to fulfil the role of sex educator. In order to begin progress in the area one respondent noted that it might be helpful if competencies for training were examined for the delivery of relationships and sexual health work as part of an overall training needs analysis.

The following were seen as key elements within any training programme;

- Building resilience, confidence and focusing on strengths.
- Building capacity to make choices and decisions.
- On-going training repeated as necessary.
- Skills transference. (Often staff felt that persons with intellectual disability can recall facts learned in theory but cannot apply these to their own lives).
- Consistent messages between services.
- Consistent messages between home and services (this means bringing parents on board with the programme).
- On-going provision to include checking whether the message is understood and can be applied practically by service users.

Training programmes should up-skill staff in accessing and developing programmes that respond to the needs of service users. Programmes must be needs driven and based on consultation with service users. Respondents felt that programmes should stem from a rights-based perspective and be informed by solid values of respect and dignity. Key ingredients of training should include;

- Time to reflect and explore personal attitudes and values in a safe space.
- Exploration of boundary issues and how to ensure staff training.
- Reflection and skills-building in relation to working and engaging with parents around relationships and sexuality education.
- Training on the policy of their organisation. This training was recommended for all staff.
- Exploration of difficult themes and ways to resolve these including debriefing – themes such as abortion, abuse etc. can be difficult and may only be resolved on a case by case basis.
- Materials and methodologies. Staff noted the need for age appropriate materials along with materials designed for specific scenarios and levels of capacity. They also need training on how to adapt existing resources.
- Measuring capacity and assessing needs in relation to RSE. Staff noted that programmes should be needs based and therefore skills are needed to assess capacity and current levels of knowledge among clients.
- Training should include information on sexual health as the level of accurate knowledge can be low among staff.
- Staff also noted the need for a training needs analysis, multi-disciplinary and multi agency training, support for staff teams and the importance of working through mechanisms already in place to deliver person centred planning.
- Opportunities to meet other agencies and network around good practice.

3.1.4 Materials and resource needs

All staff identified a need to have access to current resources and teaching materials. There appeared to be a great desire to share and provide further information on the use of resources. It was noted that staff are forever looking for resources and material to work with intellectual disabilities. Often traditional approaches to sex education are not very effective with this group due to a number of factors including; their sensitivities in relation to sexuality, the limitations of group discussions, the need to use very simple materials and the necessity to use methodologies which engage clients. Materials and programmes need to;

- Be culturally appropriate.
- Use simple language.
- Allow repetition.
- Be visual and clear.
- Include warmth, friendship and emotion – many of the resources were quite sterile.

Staff experienced in this area noted the necessity to adapt existing resources to meet the needs of those with varied ability. However there are time and resource implications in completing this type of adaptation. Key recommendations from staff included training in facilitation and adapting materials to meet the needs of persons with intellectual disabilities and learning about methodologies suitable for their client group.

3.1.5 Staff perspectives on parents needs

All respondents noted the fears and concerns of parents. This is reflective of the fears and concerns of parents throughout the world. Respondents noted that parents have three main fears;

- The fear of abuse / exploitation of their child with an intellectual disability.
- The fear of pregnancy and their subsequent responsibilities.
- A fear of isolation and loneliness as they move into an uncertain future.

All staff noted that there is a need to include and build capacity of parents around RSE. A number of successful approaches were noted by respondents. Recommendations for developing work with parents included;

- Developing a standard training pack for parents. This would include ongoing development tools for work with parents either as part of direct programmes or as part of the ongoing day-to-day dialogue with parents. These might cover parents' own anxieties, discussions on what to expect around relationships and sexuality and exploring the concept of their son/daughter as sexual beings. It would also include exploring with parents the practical implications of their children forming relationships and how the family can support better social contacts. This could also include the development of specific programmes for parents of younger children.
- Providing skills training for staff in working with parents.
- Sourcing counselling for parents (available in different agencies).
- Having parents involved in working parties. It was noted that this has a time implication as meetings have to be held at times which suit parents.
- Using a sense of humour with parents- this is a sensitive issue for many and humour can diffuse a situation.

4.0 Discussion on common themes

4.1 Sexual health for persons with an intellectual disability is a rights issue.

Throughout all of the consultations participants frequently raised the issue of human rights and equality for persons with an intellectual disability. Respondents identified with the concept of relationships and sexuality as an aspect of human rights, equal rights, health inequalities and finally as a risk management issue.

The literature review highlighted how sexual health as a human rights issue is addressed within the 2006 Draft United Nations Convention on the Rights of Persons with Disability (United Nations 2006) and the UN Standard Rules for the Equalisation of Opportunities for Persons with Disabilities. Both of these documents provide for sexuality and relationships as a right for persons with a disability. It is clear from the research that these rights are not being met. Moreover, current legislation (1993 Criminal Act) appears to specifically deny these rights. From a health inequality perspective, the literature review and this consultation shows that persons with an intellectual disability are not receiving services based on their needs and are demonstrating health inequalities as a result. Manifestations include poorer sexual health, less capacity around relationships and exposure to greater risks of abuse. This is confounded by a lack of solid research in the area and it would appear that there is very little and uneven provision of RSE as well as limited provision of screening and sexual health services. If a key goal of the population health agenda is to improve the sexual health of the population then persons with an intellectual disability form a high risk group.

Finally from a risk management perspective, the risks alone provide sufficient rationale to justify greatly increased sexual health promotion within the intellectual disability setting. The literature review and our consultations show that people with intellectual disabilities have increased risks of sexual abuse or unhealthy sexual expression for a number of reasons.

In conclusion, this research has identified a number of areas where the needs of people with intellectual disabilities are not being met. This situation raises issues around human rights, equality of treatment, freedom of expression, health inequalities and risk exposure. The research suggest that a lead agency, such as the HSE should raise these important issues with agencies that have specific remits around disability, equal rights and risk management.

RECOMMENDATION

We recommend that this research is disseminated to a broad field with specific briefings provided to;

- The Department of Health and Children.
- The National Disability Authority.
- The Equality Authority.
- The National Federation of Voluntary Bodies.
- The Health Service Executive.
- The Institute of Public Health (currently researching areas under health inequalities).

These agencies have specific remits and can advise how best the research can be used to influence changes in policy and practice.

4.2 Capacity and legal uncertainties on capacity to consent

The 1993 Criminal Act makes it is a criminal offence to have or attempt to have sexual intercourse with a mentally impaired person or to commit or attempt to commit buggery with a mentally impaired person (other than a person to whom you are married). The definition of 'mentally impaired' used by the Act describes a person with such an impairment as:

'Suffering from a disorder of the mind, whether through mental health or mental illness, which is of such a nature or degree to render a person incapable of living an independent life or of guarding against serious exploitation'.

The Act has resulted in a lot of confusion within disability services as to whether carers who facilitate a sexual relationship between service users are guilty of aiding and abetting the commission of a criminal act. In all consultations the legal uncertainties emerged as a prime issue for

all concerned. In practical terms, the Act allows those services that wish to avoid the issue of RSE to effectively ignore this aspect of care while at the same time creating great uncertainties for those who wish to provide positive and needs based responses to the issue within services.

The area of capacity to consent to sexual relations for persons with an intellectual disability will be examined in due course by the Law Reform Commission (LRC) in the context of their third programme of work. At present, this means that the 1993 Criminal Act remains valid and service providers must abide by its direction. There is a role for the HSE as a lead agency in providing direction and guidance around the concept of positive sexual health. For intellectual disability services a starting point would be initiation of a dialogue with the Law Reform Commission (LRC) and the Criminal Law Reform Division of the Department of Justice Equality and Law Reform on areas where reform is needed (specifically aspects of the 1993 Criminal Act).

As the debate on capacity becomes more developed, there will be a requirement to develop tools to assist staff in measuring capacity within relationships for intellectual disable persons.

RECOMMENDATIONS

The HSE should provide the findings of this research to the LRC and the Criminal Law Reform Division of the Department of Justice Equality and Law Reform as a vehicle to begin discussions with a view to resolving legal uncertainties arising from the 1993 Criminal Act.

There is a need for ongoing liaison relating to the development of practical tools to measure capacity. The HSE or a nominated agency should work on the development of such tools from the perspective of those providing relationship and sexual health promotion in partnership with agencies that have a specific interest in this area including the National Federation of Voluntary Bodies, ISEN, and Inclusion Ireland.

4.3 Development of policies at a national level

At present there is no national driver for sexual health promotion work within the intellectual disability sector. A national sexual health strategy is required to contextualise and prioritise sexual health promotion that would place the rights of persons with a disability at the centre of developments. The forthcoming plans for the development of a sexual health strategy are not yet finalised within the HSE.

RECOMMENDATIONS

This research should be provided to the Department of Health and Children to inform future work in the area of disability policy and sexual health policy

This research supports the work underway within the HSE to develop a national sexual health strategy.

The HSE as part of its work to develop a national sexual health policy should include persons with an intellectual disability as a high risk group.

4.4 Development of policies at an organisational level

The need for organisational policies concerning relationships and sexuality emerged as a priority need in all consultations. Organisations with developed policies spent many years engaged in a process that involved parents, service users, boards of managements and staff underpinned by extensive research.

This is not the case in all organisations and staff noted that there is a resultant inconsistency in policy and practice and a lack of protection for staff in responding to the issues. Staff noted that a policy was required in order to;

- Address inconsistencies in current responses.
- Provide a model of good practice in responding to the issue.
- Ensure the rights of individuals.
- Provide guidelines to staff on how to respond to particular issues.

- Protect staff in the context of their work with persons with intellectual disability.
- Provide clarity on key issues from a legal perspective.

The draft standards developed by Health Information and Quality Authority (HIQA) will provide a national framework to assess residential services and many of the standards cover issues relating to sexual health and relationships. These standards are welcome but will require dedicated supports to ensure their implementation. At a basic level, organisations will require a policy to guide staff on issues concerning RSE and act as a yardstick to indicate compliance with the standards in particular areas.

It was clear from this research that there is a considerable amount of duplication within agencies in their attempts to develop policies at an organisational level. Respondents also noted that this allowed agencies to develop different types of policies depending upon the concerns and biases within the agency. As a consequence this represents poor value for money. To overcome this duplication, respondents recommended that a national policy template be developed to guide and direct agencies in the development of their individual policy. This template could be adapted by individual agencies thereby allowing for differences in ethos or emphasis and create space for a process of consultation at the level of the organisation.

To be effective, this work requires a national driver to lead the development of a national template. It appears from the consultation that there is a gap in terms of initial national leadership for this work and the HSE would be best placed to initiate discussions to clarify the most appropriate lead agency.

RECOMMENDATIONS

This research supports the recommendation that each organisation should develop an organisational policy around relationships and sexuality education. This process should be guided by good practice in the field.

The HSE should facilitate discussions towards the development of a national organisational template on policy in relation to RSE. This project should be developed in partnership with the NDA, Department of Health and Children, Inclusion Ireland, the National Federation of Voluntary bodies and the ISEN. The researchers working on this project noted willingness on the part of organisations consulted to contribute towards the development of a national organizational policy template.

4.5 Consultation with service users and parents

In the original plan for this research 12 consultations were planned with service users and four with the parents of these specific service users. It was not possible to undertake this piece of the research as planned but throughout the course of the project several key learnings were gained which could usefully inform the next stage of the project which will involve service users and parents.

In regard to interviewing parents and service users it should be noted that findings from an intensive research project in Northern Ireland (NI) and Scotland (SCT) are particularly pertinent and are available on the web (FPA-NI and Health Scotland).

RECOMMENDATIONS

This research strongly supports the recommendation that the HSE continue with its commitment to consult with service users and parents of persons with an intellectual disability in order to complete a more extensive research process based on the outcomes of this research.

In order to support this research a number of related recommendations were provided to the HSE.

4.6 Training and development of standards for RSE delivery

For many staff employed within the sector, training has traditionally been delivered in an ad hoc manner to those who make specific efforts to access it. This reflects the findings from the recently

published ISEN research. Most respondents felt training should be delivered through a combination of front line staff working every day with service users and designated persons with specific training in relationships and sexuality. Respondents mentioned the value of having external trainers come into organisations to train staff such trainers brought energy. An objective perspective and were able to motivate the organisation to engage proactively with RSE.

On a very basic first level there is a need to provide training on the policy of the organisation and the importance of RSE for service users. Staff recommended that all staff receive this training.

At a second level there is a need to provide more specialized training for those staff who express an interest in becoming in-house resources around RSE. Staff recommended that these staff should be selected on a voluntary basis. They would then be able to fulfil a number of functions within the organisation such as:

- Providing basic training and education on RSE to all staff.
- Running RSE programmes in partnership with front-line staff.
- Facilitating training and discussions with parents.
- Acting as a resource and a referral point for all staff around issues concerning RSE.

At a third level there will be a need to build awareness among management in relation to the need to develop policies. Management will need to be encouraged to drive the implementation of RSE programmes and to develop clarity on legal and national developments. This training may not be ongoing but could be part of 'whole system / organisation' training. Such an approach was used by one organisation and was felt to be very successful in allaying fears and ensuring ongoing support for RSE programmes.

Finally at the fourth level there is the need to train 'trainers'. There is a heavy reliance on a small number of trainers but if and when training becomes more extensive there will be a 'capacity' issue for expert trainers. In particular trainers from the United Kingdom (UK) and Northern Ireland (NI) will be limited in their ability to provide ongoing training in the Republic of Ireland (ROI) context.

There is a need to begin to develop capacity among a group of trainers within the ROI who will be prepared to either work within organisations to train staff or run external training courses.

In discussing training for staff and service users there was unanimous agreement that training should;

- Be directed at service users at all points in the service and not just those over 18 years of age.
- Be accessible to those outside of services (e.g. those with borderline or mild intellectual disability in the community).
- Be practical and focussed on building skills among staff attending.
- Be rights based and centre on building capacity within service users.

In developing training there is a need to standardise delivery and ensure quality in training. One way to do this is to develop formal accredited training courses. Accredited courses could be directed at;

- The specialist within the service delivering training ranks.
- The specialist expert trainer. This might be a person who completes additional training or demonstrates training competencies.

An approach like this could be supported by the development of standards for the delivery of RSE. Developing such standards would provide a benchmark to measure progress and delivery. In the absence of a national standard it is difficult to critique and evaluate current levels of delivery.

Finally there is great scope to develop evaluated models of training – at present none of the training is evaluated and monitored.

There is room for more discussion regarding training needs. While the recent ISEN research will add to current knowledge, in order to deliver a sustained and resilient training programme it is recommended that a simple training needs analysis and action plan / training strategy should be developed. This should be undertaken in partnership with key resource agencies and existing trainers in the field.

RECOMMENDATIONS

We recommend the HSE takes a lead role in ensuring the development of a training needs analysis and an action plan / training strategy for delivery of RSE within the intellectual disability sector. Key partners should be engaged in establishing the content and in designing the training strategy and delivery mechanisms for training courses.

We recommend that the HSE take a lead role in ensuring in the development of a national standard for the delivery of RSE in the mild / moderate intellectual disability care setting. This could be part of the national project on organizational policy mentioned above or part of the development of the national sexual health strategy.

4.7 Materials and resources

All staff interviewed in the course of this research mentioned a need for access to resources, particularly those with visual content. They also expressed a need for opportunities to share information on developments and resources. People with wide experience in providing relationships and sexuality education felt there was no need to develop a new set of Irish materials as there are much excellent up-to-date material available from other jurisdictions. However, experienced practitioners noted that existing resources constantly need to be adapted to meet the needs of those with varied ability.

There are two options for future development. The first concerns the development of a new set of RSE resources for intellectual disability. This would incur a large time and resource implication. A more efficient approach might involve developing a training programme and toolkit designed to up-skill staff in adapting existing programmes to suit the needs of their group.

A second option would involve the development of an overall training course. Such a course would include an introduction to existing resources and a process of skill-development in adaptation informed by needs assessment.

Costs emerged as an issue within organisations given that resources required for RSE can be quite expensive. Perhaps small grants could be made available to fund (or part fund) organisations wishing to purchase particular sets.

As a way around the cost factor the HSE could provide an inventory of international and national resources already in existence and could facilitate services in learning about these and adapting them to their own care setting. Value would be added to this exercise through networking between organisations and the sharing of experiences. At a later stage it might become clearer if specific Irish resources are required.

RECOMMENDATIONS

The HSE should initiate an information sharing project designed to introduce services to a range of materials and resources available for intellectual disability with a specific focus on how to adapt materials and programmes to care settings. There are a number of ways this work could be facilitated in the short, medium and longer term. Specific ideas include:

SHORT TERM / IMMEDIATE IDEAS

- Purchase of a set of the top ten resources on RSE using the Scottish publication – *A Review of Resources* as a basis for selection for each HSE area. These could be made available to agencies perhaps through a lending / library arrangement or through the regional health promotion departments.
- Provision of a grant to agencies wishing to purchase materials.

MEDIUM TERM IDEAS

- Facilitation of a networking forum in each of the HSE areas for voluntary and statutory agencies and NLN centres working in that region (see below) and showcasing the resources available around this area.
- Creation of users email groups / online forums to share ideas and information.

LONGER TERM IDEAS

- Development of a webpage for service staff on resources available with a facility to feed in ideas and experiences.
- Facilitation of an interagency group comprising service staff / HSE group to look at the need for new Irish materials with a commitment to develop a full 'toolkit' for staff to include details on existing resources, standards/policy information and new materials.

4.8 Facilitation of networking

Staff attending the consultation found the exercise had been very useful and informative for them. They noted how they often worked in isolation and without support for engaging in service developments. In addition they noted that considerable work was required to research new approaches or programmes and ideally they should be able to learn from other organisations working in this area. They noted the need for ongoing networking between different agencies, between relationship and sexuality educators and key workers, between residential and day care centres and between those providing specific relationship and sexuality education. A key product of good networking would be a practical understanding of roles and responsibilities as well as enhanced communication and identification of areas where further needs are arising.

On a practical level, there is no single organisation with responsibility for communicating to all organisations providing services to intellectual disability. Networking needs to happen between voluntary agencies, state agencies and the national learning network. For networking to be effective one agency needs to be charged with responsibility to 'create the networking spaces'.

The consultations for this research were organised around HSE areas West, South, Dublin and Midlands; an arrangement that worked well. This might be further developed if the HSE, perhaps through health promotion services, could facilitate ongoing networking of those involved in RSE in intellectual disability care settings. Alternatively the

National Federation of Voluntary bodies would be able to advise on the most effective approach to facilitating networking.

RECOMMENDATION

The HSE should examine, in partnership with interested agencies, how it can facilitate or support ongoing networking for organisations providing services to persons with an intellectual disability. This would be a very positive follow-on from this research. It would build on the research project and lay the foundations for alliances in future partnership work.

4.9 Advocacy within senior management regarding the importance and relevance of this work

To progress issues and concerns around any one topic within an organisation as large as the HSE it is necessary to have advocates or champions for the subject. It proved difficult to engage senior / management staff from the HSE health promotion and disability sectors and their equivalents within voluntary agencies around this piece of research. Unlike other health issues such as smoking or breastfeeding where there are national drivers there is no national driver for this type of work, nor a national mandate to provide RSE within the care setting. From the perspective of the HSE there is a need to 'house' this work within a particular directorate so that it is seen as an organisational priority and part of the responsibility of senior staff.

In establishing contact with the voluntary agencies most of the contacts made as part of this research were new. In contacting the agencies it was clear there was no history of partnerships between the HSE / population health and services providers around the sexual health promotion for persons with an intellectual disability. Indeed it was noted by the agencies themselves that the disability services mainly deal with the Primary, Continuing and Community Care directorate (PCCC) for funding arrangements. In order to engage voluntary agencies around this issue and to obtain their commitment for future work, advocacy at senior levels will be required from the HSE – this issue

needs to be seen as an organisational priority for the HSE. In practical terms this means that discussions need to happen between senior staff of the HSE and voluntary agencies. On a more positive note, there appears to be a willingness on the part of staff and management within agencies to engage around this topic.

RECOMMENDATION

It is recommended that the HSE develop a realistic action plan to progress the recommendations and further develop models of good practice within Ireland.

4.10 Research and progressing research

In addition to the research with service users and their families a number of areas were noted as worthy of future research. This present research will most likely provide a strong rationale for further developments in this area. Within all consultations respondents noted that special schools were lacking programmes, teacher training programmes and overall resources to progress relationships and sexuality education. Their experience was that those entering adult services have little previous exposure to RSE. They recommended that RSE be included for those under 18 years of age.

We suspect that the low levels of RSE as reported to us is most likely a function of a low level of overall provision of social and personal health education within this setting. However there was no research available to validate either the statements made by respondents or our own observations.

RECOMMENDATION

We recommend that in addition to further research with service users and their families, specific research should be undertaken within the special school setting with teachers, management, service users and their families.

5.0 Final conclusion

The research shows that a number of key areas will need to be developed;

- The development of a political will to ensure that national agencies are aware of their responsibilities to develop and drive national policy and ensure the provision of relationships and sexuality education within care settings.
- Development of guidance and tools to create positive rights-based policies within organisations.
- Development of programmes of training for staff working in care settings to ensure they are comfortable and equipped to provide relationships and sexuality education.
- Development of programmes of training for service users to be delivered within or outside of care settings.
- Development of programmes to ensure that staff working within specific sexual health services are aware of the needs of persons with intellectual disability.
- Development of evaluation frameworks to ensure that work in this area can be evaluated appropriately and that learning can be shared with other organisations.
- Development of further research around many of the issues identified within the available literature as requiring further exploration.

Appendix 1: Summary of main themes from literature review

This literature review was completed in 2007. Small updates were made in 2009. The review is available from the HSE.

Introduction

Sexuality and sexual health promotion for persons with a mild to moderate intellectual disability is a complex and evolving issue.

This literature review sought to capture the emerging trends around theoretical approaches, policy development, and trends in health services delivery as well as providing an insight into current research on knowledge, attitudes and behaviours amongst staff, parents and service users.

Within the literature review, intellectual disability is defined as a condition of arrested or incomplete development of the mind which is especially characterised by the impairment of skills manifested during the development period, contributing to the overall level of intelligence i.e. 'cognitive language motor and social abilities'. In Ireland the prevalence of intellectual disability is 2.26 per 1000 for mild intellectual disability and 2.43 per 1000 for moderate disability. However these figures are sourced from the National Intellectual Disability database which acknowledges that persons with mild or borderline intellectual disability who are not receiving services are not represented on this database. The Physiological Society of Ireland estimates that a more accurate prevalence of mild intellectual disability is likely to be 8 per 1000.

Intellectual disability services are provided in the main by voluntary organisations. Many provide day programmes, which are availed of by almost 16,000 people, of which 43% have a mild level of intellectual disability and 47% are aged 18 years or under. In comparison full time residential services are used by nearly 8,000 people of whom fewer than 20% have a mild intellectual disability.

Over the past decades there have been major changes in how services are delivered with the current emphasis focusing on the principal of normalisation and ensuring that persons with intellectual disability have as normal a life as possible.

Within the literature review definitions of sexuality, sexual health and sexual health promotion are provided. The WHO working definition of sexual health is as follows: *'A state of physical, emotional, mental and social wellbeing related to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sex experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled.'* (WHO 2004)

All work around sexuality and sexual health acknowledges that there are wide influences on sexual health including economic, societal, political and educational influences.

Policy Developments

International developments

Internationally there have been a number of developments, which seek to protect and ensure the rights of persons with intellectual disability. Most recently the *Draft United Nations Convention on the Rights of Persons with Disability* (the United Nations 2006) specifically states that for persons with a disability there should be respect for home and family and it specifically enshrines the right to be allowed to marry and have children. This was ratified by the Irish Government in March 2007. At present services still rely on the *UN Standard Rules for the Equalisation of Opportunities for Persons with Disabilities* which specifically explores the concept of sexuality and the rights for persons with the disability to explore their sexuality. Internationally the Centre for Reproductive Rights has produced material which draws together all international agreements treaties and conventions. This is a very useful review in relation to sexuality and disability.

These international agreements explore the concept of sexual health as a right. Several researchers have argued that while it agreed in principle that people with intellectual disabilities have the right to sexual expression, there is much uncertainty concerning the exact nature of such a right. Their rights are not protected within the national or organisational policies governing their care and to be meaningful the concept of rights needs to be embedded in the policies and procedures of organisations.

In summary, there is strong international consensus to support the development of rights-based policies and approaches.

Within an Irish context the National Disability Act 2004 establishes a system for the assessment for individual health service and educational needs. However there is no statutory requirement to provide all the services identified. In 2008, the Health Information and Quality Authority produced their draft National Standards for Residential Disability Services. Whilst these are draft at present they do outline the supporting criteria against which services will be measured.

In all debates about intellectual disability and sexual health the concept of capacity to consent is debated. A key question is whether persons with an intellectual disability have the capacity to consent to relationships and in particular sexual intercourse. In Ireland this is further complicated by the Criminal Law Sexual Offences Act, 1993, which states that it is a criminal offence 'to *have or attempt to have sexual intercourse with a mentally impaired person or to attempt to commit buggery with a mentally impaired person (other than a person to whom you are married)*'. The Act has resulted in a lot of confusion within disability services as to whether carers who facilitate a sexual relationship between service users are guilty of aiding and abetting the commission of a criminal act and creates uncertainty regarding the status of policies and programmes.

In 2005, the Law Reform Commission produced a Consultation Paper on vulnerable adults and the law in relation to capacity (LRC CP37-2005), and as part of this, explored capacity to consent to sexual relationships. Their work has resulted in the publication of the Mental Capacity Bill which provides clearer direction around the issue of capacity for vulnerable adults. However, as recommended by the LRC, this bill specifically excludes any consideration in relation to capacity to sexual relationships, as the commission felt at the time that this area was a very complex area and required a programme of work in its own right. As such the areas of capacity to consent to sexual relations for persons with an intellectual disability will be examined in due course by the LRC in the context of their third programme of work. At present, this means that the 1993 Criminal Act remains valid and service providers must abide by its direction. From a practical perspective this clearly creates a dilemma for many providers.

The available research literature acknowledges that it is very difficult to measure capacity to consent and existing tools are poor. International literature in the area indicates that underlying assumptions can influence the outcomes of measures to determine capacity and attempts to provide an objective evaluation of capacity to consent to sexual expression can lead to different outcomes. Recent Irish research completed by Evans (2002) shows the need for tools to assist staff in establishing the type of relationship a person is capable of where relationships are consensual. International literature in the area indicates that underlying assumptions can influence the outcomes of measures to determine capacity and attempts to provide an objective evaluation of capacity to consent to sexual expression can lead to different outcomes.

Development of policies within organisations at a national level

Many authors argue for the need for strong policy at an organisational level so that people know where they stand; parents are aware what practices are permitted; staff are aware of their professional obligations; and clients know their rights and responsibilities. Many organisations have developed organisational policies to look at sexual health and intellectual disability. However, there is no national drive to develop policies, and the motivation for policy development rests with individual organisations. The literature review examines what constitutes good organisational policy. In addition to the international evidence supporting the need for a rights-based approach, good organisational policy should spell out an agency's position on a variety of sexual issues and put boundaries around staff behaviour. Policies should be relevant, meaningful and helpful to clients and direct care employees, and be supported through training and review.

Many authors have argued that the process around the development of policy is just as important as the policy itself. Those with experience around developing policies recommend the adoption of a consultative approach, which incorporates the views and opinions of service users, parents, staff and management. There are considerable resource implications in developing good policy, as time needs to be allocated to facilitate proper consultation.

Implications for policy and practice

The literature review provides strong support for the development of rights based policies at organisational and national level. In essence the international agreements, of which Ireland has been a part, provide the starting points from which to develop good policies. The research to date strongly supports the development of policies both at a national and more specifically at an organisational level. There is clear guidance and examples upon which to develop good policies but the literature has also captured some of the difficulties around policy development such as the need to dedicate sufficient resources and time to ensure proper consultation and meaningful engagement with service users and their families.

Finally, once legal issues in relation to capacity are progressed, service providers will require robust and simple tools to measure capacity.

Attitudes towards the sexuality of people with intellectual disability

This section of the literature review examines some of the historical developments around sexuality and intellectual disability and looks at current research around the attitudes of staff and parents.

Historical and societal perspectives

Historically the sexuality of persons with intellectual disability was seen as problematic and to be feared. There was a strong emphasis in the past on the eugenic movement which meant that many persons with intellectual disability were sterilised without their consent. This practice began to be challenged in the late 20th Century and rarely is practised today.

Current research indicates that societal attitudes towards sexuality of people with intellectual disability can be positive, with many people accepting that persons with intellectual disabilities are entitled to much the same opportunities as everyone else. However, there is still evidence of 'mixed feelings' in this regard primarily centring on the notion of capacity. For example, in a Special Olympic Survey 2003, 53% of Irish respondents thought that people with intellectual disabilities were capable of marriage but only 23% believed they could raise children.

Other research has shown huge variances between the values and attitudes of staff around the sexuality of persons with intellectual disability. The opinions of staff members are crucial in any work around intellectual disability as they have a powerful role in the lives of people with intellectual disability. A key finding has been that although staff may have positive attitudes towards the sexuality of persons with intellectual disability this does not always predict whether these attitudes influence their provision of sex education. Many staff members are reluctant to provide sufficient sex education for fear of reprisal from parents or the organisation and concerns around the capacity of the individual.

Some of the papers reviewed show that those working in mainstream sexual health services report feel uncomfortable and fearful of working with persons with intellectual disability and their families on issues of sexuality. For many this stems from viewing persons with intellectual disability as being vulnerable and at risk of being sexually abused. Studies to date highlight the need for disability awareness training for sexual health professionals.

Parents

For the most part parents are the primary carers for persons with intellectual disability. The research indicates that sexuality is a major issue for parents of children with intellectual disability, with concerns generally revolving around possible exploitation, inappropriate behaviour and a fear of pregnancy. Some research reports that such parents are more likely than parents of non-disabled children to be resistant to their child's sexuality believing that their children are permanent children and thus asexual. In Evans (2002) study the parents interviewed did not believe that the person they cared for was capable of intimate relationships. However, other recent research has shown that parents primarily want their son or daughter to be happy, not to be lonely and to have someone special. Their primary concern is the protection of their son or daughter. Researchers argue that organisations for people with intellectual disabilities have a role to play in informing and educating parents or carers.

Implications for policy and practice

The current research on the attitudes of staff appears to show that there may be variances in the attitudes of staff at an organisational level. This points to the need for standardised training to ensure that the values and attitudes of staff do not influence the provision of relationship and sexuality education and the guidance provided to service users.

The research also shows that more time may need to be allocated towards reaching those staff least likely to volunteer for training courses, in addition to spending more time exploring staff attitudes and values as a part of training.

It is clear from the research that parents have real concerns about the sexuality of their son or daughter. Any work completed within organisations around this area must include and involve parents and recognise that parents may need support and assistance in coming to terms with and supporting their son or daughter's sexuality.

Sexual development in people with intellectual disabilities

The literature shows that sexual development for people with mild and moderate intellectual disabilities is by and large normal and similar to that of the general population.

Sexual health knowledge

The literature shows, however, that people with intellectual disabilities are rarely allowed to express their sexuality in a normal healthy manner unless they are living in respectful and supportive environments. The literature review describes in detail available Irish research looking at the attitudes, knowledge and experiences of persons with intellectual disability. The review focuses specifically on recent Irish research, (Caffrey 1992, Holland 2004, DeRossa 1994, Evans Healy and McGuire 2002). In general, persons with an intellectual disability show low levels of knowledge and awareness around all matters of sexual health, body awareness, contraception and relationships. The literature shows that while some people have some understanding about sexual intercourse there remains a lot of misunderstanding as to the actual mechanics of sexual intercourse and pregnancy. There is a clear warning in some of the literature with DeRossa (1994) reporting that a lack of knowledge about pregnancy *'could result in people engaging in sexual intercourse without understanding the possible consequences, or such misunderstanding might prevent people from engaging in other activities such as kissing, if they believe this activity can result in pregnancy.'*

On the whole the attitudes of people with intellectual disabilities towards masturbation appear to be conservative or negative and illustrate guilt and stigma surrounding this behaviour. These low levels of knowledge and awareness contrast starkly with the desires and aspirations of persons with intellectual disabilities to form relationships. In all research, participants report a strong desire for intimate relationships.

In addition, some of the research to date shows that many people with intellectual disabilities do engage in sexual activity. In Caffrey's (1992) study, participants had positive attitudes towards sexual intercourse even though the majority knew little about contraception and were unlikely to engage in intercourse. The research shows that persons with intellectual disability are often confused regarding the appropriateness of certain behaviours and lack accurate knowledge and awareness of their ability to engage in appropriate sexual behaviours.

The Irish research available shows that people with intellectual disabilities are likely to face negative attitudes from their peers. This has implications as people may not know how to express their sexuality or may feel limited in asking others for help and information.

In relation to marriage and the creation of a family much of the research shows that persons with intellectual disability have a desire to get married but that many have a limited understanding of what people do when married. In addition many do not believe that either will happen for them.

Throughout the research many barriers around safe sexual expression are identified. Some of these relate to misinformation. This includes information which may be withheld from persons of intellectual disability because of a belief that such information is not relevant. Alternatively, they may be provided with misinformation in order to curb certain behaviours e.g. masturbation. Misinformation has implications for persons with intellectual disability as they may engage in behaviours without fully understanding the consequences for themselves or others. The research indicates a need to provide accurate information to people with intellectual disabilities and also a need to provide information for parents and staff.

Another barrier articulated within the literature towards people with intellectual disabilities forming relationships is the attitude of their families. This can result in over-protection by the families with the result that people with intellectual disabilities rarely have the opportunities to meet others.

Finally, disability services themselves can act as a barrier to the formation of relationships. Loneliness is a key factor in the lives of many persons with intellectual disability. The research highlights a recurring theme that persons with intellectual disability are limited in their opportunities to form relationships and many view the services as their key social outlet. The research shows that services themselves can act as a barrier to the formation of relationships either through supervision or rules about behaviours. The research recommends that services may have to develop their ability to facilitate the formation of relationships (of all kinds) as many of those availing of their services may have limited opportunities to develop such relationships in other settings.

In conclusion, it is clear that persons with intellectual disability do not have sufficient levels of knowledge regarding sexual health. This low level of knowledge extends to knowledge about all matters. This could be damaging to their future health and well-being and does not correspond to their desires to form relationships or their level of sexual experimentation and activity.

Sexual health of people with intellectual disabilities

The research to date shows that this is an area which has been poorly researched and requires more systematic and focused research. It is clear that best practice for providing sexual health services will be limited in their establishment if there is not sufficient evidence from quality research. Research that is available (although limited) shows a number of key findings.

Self-esteem and self-image are important components of positive sexual health. However, much of the research shows that persons with intellectual disability often do not see themselves as adults even if they show the sexual preferences of adults. This emphasises the need for people with intellectual disabilities to be given clear and factual information regarding their sexuality in order for them to be able to behave as responsible adults when engaging in interpersonal relationships.

In relation to menstruation, Irish studies have highlighted that many women with intellectual disabilities have difficulties managing the symptoms of menstruation and this can be sited as a 'difficult to manage' issue for staff. However, other research has shown that education and supports are effective in supporting and educating service users around their menstrual self care.

In relation to the menopause, the limited research available shows that there is a considerable lack of knowledge around the menopause for women and this can be a cause of increased stress for women at this time of their lives.

In relation to contraception and the use of contraceptive services the research is particularly limited. It is clear from the research that this is an area which has been over shadowed by debates about reproductive freedom and the rights of women with intellectual disability to reproduce. It is a highly sensitive debate and one which has not been fully explored within an Irish context. The research that is available shows that sexually active persons with intellectual disability have a desire to receive more information around contraception. There is a clear need to reconcile the levels of sexual activity with skills and knowledge to protect sexually active persons from unwanted pregnancies and to exercise reproductive choices. There is no Irish information on the fertility rates of persons with intellectual disability or on sterilisation.

In relation to STIs and HIV/AIDs, the research shows that persons with intellectual disabilities who are engaging in sexual activity are at high risk of STIs as they are less likely to receive general education, information and resources to ensure safer sex. In addition they often have limited access to affordable care should they become HIV positive. This is an area which may become a greater concern as the experience of heterosexuality and homosexuality is often hidden among persons with intellectual disability. In relation to homosexuality, many educational resources do not properly explore and define this issue and understanding is further limited.

The issue of sexual abuse is heavily debated within the research literature with a strong emphasis on discussing this topic (to the detriment of all other aspects of sexual health). The most powerful Irish study was that completed by McCormick *et al.*, 2005, which shows that sexual abuse is a reality within services. In their study almost half of 250 allegations of sexual abuse examined were confirmed. More than half of the perpetrators were adolescents and adults with intellectual disabilities. A frightening finding among this research was the level (about 10%) of people with intellectual disabilities who thought it was appropriate to engage in intimate touching with family members or strangers. The results within the literature clearly illustrate a need to ensure that persons with intellectual disability are protected through knowledge and skills, with clear organisational policies and guidelines against potential sexual abuse.

The literature review briefly explores gender issues and shows that women with intellectual disabilities experience more restrictions and controls in their social and personal environment than do men of similar ability levels. However, it must be noted that the literature is very limited in this regard. In particular the literature around men is very limited and primarily focuses on deviant sexual behaviour of men. The literature always also shows that female staff members are much more likely to attend training courses around relationships and sexuality which means that boys and men with intellectual disabilities are either getting their needs met in this area by women or they are receiving education from male care givers who are not well informed and up to date with the issues.

Sexual health promotion for persons with an Intellectual disability

There is no national relationships and sexuality programme adapted to the needs of people with intellectual disabilities outside of mainstream education. The National Council on Curriculum and Assessment (NCCA) have developed curriculum guides on social personal and health education (SPHE) for mild, moderate and severe intellectual disability.

A study by the Irish Sex Education Network shows that the majority of people under and over 18 with intellectual disabilities receive little sex education. This is despite of evidence of a strong rationale which shows that the provision of accurate knowledge and information to persons with intellectual disabilities is a mechanism to protect them from exploitation and unwittingly offending others.

Sexual health promotion programmes described in the literature have been implemented to achieve a wide range of objectives, and have usually included individuals with mild to moderate intellectual disability taught in groups in relatively short sections over a period of several weeks.

The primary purpose of the programmes has been to improve social skills related to levels and degrees of personal interactions, improve knowledge of sexuality facts, teach abuse prevention tactics and to provide information about specific issues such as how to manage menstruation or to avoid STIs. Commentators have noted that most programmes do not seek to improve attitudes towards sexuality. In addition many commentators criticise programmes as being overly focused on biological functions. The literature review briefly examines some of the considerations in providing relationships and sexual health education including timing, the importance of choosing and adopting curricula and assessing needs before the programme commences.

A key weakness identified in the literature is the lack of evaluated programmes. Indeed there do not appear to be any evaluation frameworks available for programmes. Most programmes are not evaluated and therefore learning from previous work and other's experiences is not available within the research literature. This is a clear area for development with a specific need to develop evaluation frameworks to cover not just changes for persons with intellectual disability but also parents and staff.

There is some research available which shows that training provided to staff working with persons with intellectual disability can be effective in improving attitudes and values about the rights of persons with a learning disability around issues concerning sexuality. Staff who have taken training courses are often more open to adults' clients expression of sexuality and to clients having children. However, this is an area which requires further research. In addition there is very little research available, particularly in the Irish context, concerning the levels of training of sexuality educators.

Implications for policy and practice

Available research shows that persons with intellectual disabilities have both aspirations to form relationships and experience in both sexual and non-sexual relationships. This contrasts with the poor level of knowledge shown in research regarding all matters of relationships and sexual health. Clearly there is a gap identified through this literature review, which shows that if persons with intellectual disability are to be adequately protected by those who care for them, then they must be provided with the information and skills around relationships and sexuality. This has implications for the development of programmes, further illustrates the need for policies and gives a mandate to support for the development of relationships and sexuality education (RSE) within care services.

There is a need to develop evaluation tools and frameworks and to encourage the completion of research projects including publication in peer journals.

Good practice indicates that in developing programmes a significant amount of time should be spent in adapting and testing approaches. These considerations have resource implications for organisations such that time must be devoted to planning and monitoring programmes.

Final conclusions

The major themes that emerge in the literature are;

- There is little policy within the area of sexuality and health promotion for persons with an intellectual disability and there are major legal barriers to the development of policy within an Irish context. In comparison, strong policy does exist around the area of protection against sexual abuse.
- The lack of policy has implications; at the very least, many persons with an intellectual disability are being denied a basic human right to form relationships. Contemporary policy is moving towards an emphasis on rights and promotion of sexual health.
- The sexuality of persons with intellectual disability is more often considered as a problem than as a normal human condition by parents, caregivers, and the general public.
- There is comparatively less knowledge about the sexual needs of persons with intellectual disabilities and their intimate relationships than for the general population.
- Individuals with disabilities seem to have little knowledge about sexuality matters and little opportunity to make personal decisions and choices about intimate relationships. On the other hand, they have the same aspirations towards relationships as the general population. Their lack of knowledge places them at particular risk of sexual abuse, unhealthy relationships and poorer mental health.
- One of the challenges for services for people with intellectual disabilities is how to meet the twin objectives of sexual empowerment and protection. Keywood (2003) comments: 'Where choices have been available between facilitating the sexuality of people with learning disabilities and protecting them from unwanted sexual encounters, services have typically sought to prioritise protection over empowerment'.

Appendix 2: Experts Consulted – One to one interviews

Professor Gerard Quinn, Director of the Centre for Disability Law & Policy, NUI Galway School of Law

Ms. Patricia Rickard Clarke, Commissioner with the Law Reform Commission

Ms. Mary Van Lieshout, Head of Research & Standards; Mr. Erik Koornneef, (former) Senior Standards Officer of The National Disability Authority

Mr. Brian O'Donnell, Ms. Maria Wallis and Ms. Edel Tierney, CEO and Directors of Research of the National Federation of Voluntary Bodies

Ms. Lisa Kelly, Advocacy Officer – Inclusion Ireland

Professor Kelly Johnson, Centre for Intellectual Disability at Trinity College Dublin (previously Director of the Living Safer Lives Project, Australia)

Ms. Frances Sheerer, National Co-ordinator for Relationships and Sex Education (RSE) – Department of Education and Science

Dr. Deirdre Fullerton, Health Scotland Research Fellow / Independent Researcher

Ms. Deirdre Seery, Director of the Sexual Health Centre, Cork City (UC Lecturer and member of ISEN)

Mr. Gert Job, Independent Trainer and Facilitator – RSE for persons with Intellectual Disability

Mr. Andrew Fagan, Health Information and Quality Authority (HIQA)

Ms. Meghan Doherty, Irish Family Planning Association (IFPA)

Ms. Grace Kelly, PhD Student research student, UCC

Ms. Helen Crowley, Irish Sexual Education Network (ISEN) & Coordinator, RUA, The Callan Institute, St. John's of God Hospitaller Services

Ms. Fiona Coffey, Brothers of Charity Galway

Ms. Niamh Holland St. Michaels House

Ms. Breda Crehan-Roche, CEO Ability West

Appendix 3: Service providers who attended group interviews

Committee Members of the Irish Sex Education Network (ISEN)

Family Planning Association of Northern Ireland (SKY Project) representatives

National Learning Network representatives

Health Scotland representative

Irish Family Planning Association (IFPA)

Crisis Pregnancy Agency

General Sexual Health Service providers group interview – round table discussion chaired by the National Disability Authority on Scheme of Mental Health Capacity Bill, January 29-07-2009

Appendix 4: Service providers who attended consultations or completed a questionnaire

Brothers of Charity Services in Galway, Clare, Limerick, and Waterford

Brother of Charity Respite Services (Southern) in Bandon, Upton and Wilton

Cheeverstown House Dublin 6W

Co. Wexford Community Workshop (New Ross)

COPE Foundation

Galway Association

KARE

Kerry Parents & Friends Association

Midway Services

Moorehaven Centre

Peacehaven Trust

Prosper Fingal Ltd

RehabCare

St. John of God Hospitaller Services

St. Joseph's Foundation

St. Michael's House

Stewarts Hospital Services Ltd

Walkinstown Association

Western Care Association

Windmill Therapeutic Training Unit

Daughters of Charity Services Limerick

Dara Residential Services

CoAction West – West Cork

Sunbeam

Sisters of Charity of Jesus and Mary, Moore Abbey

Drumlin House

St. Raphael's, Cork

National Learning Centres, Castlebar and Sligo

Appendix 5: S.P.R.I. – Strategic Planning and Reform Implementation

Members:

Ms. Janet Gaynor Assistant Health Promotion Manager HSE North East (Chair)

Ms. Sharon Parkinson Senior Health Promotion Officer HSE South (Project Manager)

Ms. Catherine Byrne Health Promotion Officer HSE South (Project Manager)

Ms. Máire O’Leary Health Promotion Officer HSE South

Ms. Gráinne Wolfe Health Promotion Services HSE Dublin

Additional support:

Mr. Martin Grogan Health Promotion Officer HSE South (Project Management Support)

Final Note

The author would like to thank the many others who assisted in facilitating this research both as experts on the subject matter or through allowing access to staff and facilities for consultation – our thanks are extended to all who assisted.

Bibliography

The following texts are cited within the literature review and general document. A more extensive bibliography is available as part of the literature review from the HSE (Department of Health Promotion, HSE South) References to programmes developed by agencies are not cited as these are subject to change by the agencies concerned and are often not published. These are best sourced directly from agencies themselves.

- Barron, S. & Mulvany, F. (2005) Annual Report of the National Intellectual Disability Database Committee 2005. Dublin: Health Research Board.
- Caffrey, S. (1992) S. A. M. & S. U. E. Sexual Attitudes Measured & Sexual Understanding Explored. Submitted in fulfilment of the requirements for the degree of Doctor of Philosophy (Ph.D). Dept of Psychology, Trinity College Dublin: Unpublished Ph.D. thesis.
- Center for Reproductive Rights (2002). Briefing paper. Reproductive Rights and Women with Disabilities. A Human Rights Framework. (Available on http://www.reproductiverights.org/pdf/pub_bp_disabilities.pdf)
- Department of Justice Equality and Law Reform (2008) Scheme of Mental Capacity Bill2008. Available online at <http://www.justice.ie>
- De Rossa, N. (1994) An Investigation of the Socio-sexual Knowledge Needs and Experiences of Adults with Mild and Moderate Mental Handicaps. Unpublished dissertation submitted in part requirement for the degree of Master of Science in Clinical Psychology. Belfast: School of Psychology, Queens University.
- Evans, D.S. (2002) The Development of Personal Relationship and Sexuality Guidelines for People with Learning Disabilities. Final report prepared on behalf of Galway Association by the Dept of Public Health Western Health Board. Ireland: Western Health Board.
- Evans, D.S., Healy, E. & McGuire, B. (2002). The development of Personal Relationship and Sexuality guidelines for People with Learning Disabilities. Galway County Association for Mentally Handicapped Children and Dept. of Public Health, Western Health Board. Paper presented at the Inaugural NDA Disability Research Conference. Using Emancipatory methodologies in disability research. Dublin December 2002.
- Health Service Executive (2005) Trust and care. Policy for Health Service Employers on Upholding the Dignity and Welfare of Patient/Clients and the Procedure for Managing Allegations of Abuse against Staff Members Available online at www.hse.ie
- Simpson A, Lafferty A and McConkey R. (2007) for the Family Planning Association, Northern Ireland (SKY project); Out of the Shadows; A report of the sexual health and wellbeing of people with learning disabilities in Northern Ireland. Available online from <http://www.fpa.org.uk/Shop/Learningdisabilitiespublications>
- Government of Ireland (1993) Criminal Law (Sexual Offences) Act 1993. Ireland: Irish Statute Book Database. <http://www.irishstatutebook.ie/ZZA20Y1993S5.html>
- Government of Ireland (1999) National Disability Authority Act 1999. Ireland: Irish Statute Book Database. http://www.irishstatutebook.ie/1999_14.html
- Government of Ireland. (2005) National Disability Act. Ireland: Irish Statute Book Database. http://www.irishstatutebook.ie/1999_14.html
- Groce, N and Trasi R (2004) Rape of individuals with disability. AIDS and the folk belief of virgin cleansing. Lancet 363. 1663-1664
- Health Scotland: Wellbeing in sexual health; WISH (2007)The Sexual Health Needs of Young People with Learning Disabilities, WISH, 2007. Available from www.healthscotland.com/WISH)
- Health Scotland. (2008) Sexual Health and Relationships; A Review of Resources for people with learning disabilities. Available online at www.healthscotland.com
- Health Information and Quality Authority. (2009) National Quality Standards: Residential Services for People with Disabilities. Available online at <http://www.hiqa.ie>
- Holland, N. (2004) A Study of Service Users' Knowledge of, and Attitudes to, aspects of their Sexuality. Unpublished thesis. Submitted in Partial Fulfilment of the Requirements of the Psychological Society of Ireland's Diploma in Professional Psychology (Clinical).
- International Disability Alliance; Position Paper on the Convention on the Rights of Persons with Disabilities (CRPD) and Other Instruments. 2008. Available online at http://www.internationaldisabilityalliance.org/working_groups.html

Cited bibliography continued

Irish Sex Education Network, The Current Status of Sex Education Practice For People with an Intellectual Disability in Ireland: The Sexual Health Centre on behalf of the Irish Sex Education Network. In conjunction with the Crisis Pregnancy Agency and the National Disability Authority. DRAFT REPORT. December 2006.

Keywood, K. (2003) Supported to be Sexual? Developing Sexual Rights for People with Learning Disabilities. *Tizard Learning Disability Review*, 8(3), July 2003.

Law Reform Commission (2005) Consultation Paper on vulnerable adults and the law in relation to capacity (LRC CP37-2005). Available on: <http://www.lawreform.ie/publications/consultpapers.htm>

Law Reform Commission. Report: Vulnerable adults and the law, (LRC 83 - 2006) Ireland. Published 2006. Law Reform Commission. Dublin. Available on: <http://www.lawreform.ie/publications/consultpapers.htm>

McCormack, B., Kavanagh, D., Caffrey, S. & Power, A. (2005) Investigating Sexual Abuse: Findings of a 15-Year Longitudinal Study. *Journal of Applied Research in Intellectual Disabilities*, 18, 217-227

National Disability Authority (2003b) Draft National Standards for Disability Services. January 2003. Dublin: NDA.

National Disability Authority. (2006) Capacity and the Convention: Report of NDA seminar on the draft UN Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities 15 June 2006. Available online at www.nda.ie

National Council for Curriculum and Assessment (2007) Guidelines for Teachers of Students with General Learning Disabilities (2007). Available online at www.ncca.ie

Psychological Society of Ireland (PSI) (2005) "Draft" Position Paper on People with Mild Intellectual Disability (MID), 11/11/2005. www.psihq.ie/DOCUMENTSMILDpaper.PDF

Special Olympics (2003) Multinational Study of Attitudes toward Individuals with Intellectual Disabilities. General Findings and Calls to Action June 2003.



Health Promotion Department
Eye, Ear and Throat Hospital
Western Road
Cork City
021-4921641
HPD.South@hse.ie
www.hse.ie

ISBN 1-901001-92-X
978-1-901001-92-1

© 2009 HSE SOUTH

AUGUST 2009