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Lifelong Learning Programme

This project has been funded with support from the European Commission. This publication reflects the views only of the author, and the Commission cannot be held responsible for any use which may be made of the information contained therein.

SEAD Project Country Comparison Report

Introduction

The Sex Education and Adults with Disabilities (SEAD) Project is working towards making education about sexuality and relationships accessible to adults with learning/intellectual disabilities. The SEAD project is funded by the European Union Grundtvig Programme and includes project partners from seven European countries – Belgium, Germany, Hungary, Finland, Lithuania, the Netherlands and the UK. The project runs from October 2012 until September 2015. We began by researching the current situation in six of the partner countries (Germany, Hungary, Finland, Lithuania, the Netherlands and the UK). This report describes this work and compares access to sex education for adults with learning/intellectual disabilities in each of these countries. It begins briefly by discussing terminology and the historical background to how people with learning/intellectual disabilities' sexuality is currently understood and then moves on to discuss how the six Country Reports were prepared before comparing and contrasting the findings from each of these countries.

Terminology

The SEAD project is researching and developing resources for sex education for people for whom mainstream sex education resources are inaccessible. Deciding on terminology has not been straightforward. We wanted to reflect terminology which was accessible to the people concerned, some of whom prefer 'learning disability' terminology. However, internationally the term 'intellectual disability' has been gaining favour (Schalock et al 2007), particularly in work which crosses national boundaries. Taking account of both of these perspectives, we decided to adopt 'learning/intellectual disability' terminology. We understand this to be:

> *'… a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development' (WHO Europe 2013).*

We do not however view disability as being the 'problem' of the individual. With the right opportunities, education and support, people can be enabled to participate more fully in mainstream society. The SEAD project is working from a social model understanding of learning/intellectual disability (Oliver and Barnes 2012). In the same way as wheelchair users are disabled by stairs and the lack of ramps or lifts, people with learning/intellectual disabilities are disabled by inaccessible communication and the lack of education, support or opportunities for inclusion; this applies as much in the area of sexuality and sex education as it does in other areas of life.

Background

Recent policy changes have resulted in improved opportunities for many people with learning/intellectual disabilities living in European countries; for example, the right for full and effective participation and inclusion in society (UNCRDP 2006, Article 3c; Council of Europe 2006; European Commission 2010). Unfortunately, societal attitudes have changed less in relation to sexuality and disability. Even today, there may be little acknowledgement that adults with learning/intellectual disabilities have sexual feelings,

needs and desires and many young people with learning/intellectual disabilities do not receive sex education in school or at home. In addition, in many European countries, sex education is not a formal part of the education of the staff (social workers, social pedagogues etc) who work with people with learning/intellectual disabilities (Mansell et al 2007; CHANGE 2010; Katalinić et al 2012). Staff and parents of people with learning/intellectual disabilities may find it difficult to even begin talking about sex with adults with learning/intellectual disabilities. At a time when there are increased concerns about the abuse of people with learning/intellectual disabilities (Robinson and Chenoweth 2012; Oakes 2012) it is important that sex education resources are available for all three groups – people with learning/ intellectual disabilities themselves, their parents, and the staff who work with them.

Building on previous work in this area undertaken by project partners (CHANGE 2010; FOCAL 2011), the SEAD project has been exploring how the sexuality of adults with learning/intellectual disabilities is understood in the partner countries and researching current arrangements for sex education for people with learning/intellectual disabilities. Later aspects of the project will explore innovative resources for sex education for adults with learning/intellectual disabilities with a particular focus on creative arts approaches.

The Country Reports

Project partners from Germany, Hungary, Finland, Lithuania, the Netherlands and the UK were responsible for preparing a 'Country Report' about the current situation in their country. Desk-based research was undertaken to collate information regarding the historical background to the sexuality of people with learning/intellectual disabilities in each country, including the history of institutionalisation, deinstitutionalisation and community care. Each partner also conducted up to 20 interviews (face-to-face, by telephone or email). Interviewees included local authority and Non-Governmental Organisation representatives, service providers/staff, adults with learning/intellectual disabilities and parents. Guidance notes were produced to co-ordinate data collection; these included questions for the desk based research and interview questions which covered the legislative and policy background, funding, service provision, abuse and safeguarding of adults with learning/intellectual disabilities, current arrangements for sex education and any changes or developments the interviewees would like to see. A 'Country Report Template' was also developed by the University of Sheffield, in the UK, to record a summary of the data collected. Ethical approval was granted by the University of Sheffield, with partners in other countries taking responsibility to ensure that they complied with ethical and data collection requirements in their own country. Using the 'Country Report Template', project partners produced a summary of the data collected and arranged for this to be translated into English.

Discussion of sexuality and sex education is a sensitive area – more so, when this discussion is about the sexuality of people with learning/intellectual disabilities who, historically, were 'hidden away' in institutions, often to prevent them having sexual relationships (Ryan and Thomas 1987, Tilley et al 2012). Although many people with learning/intellectual disabilities have now left the institutions, rates of deinstitutionalisation vary across Europe (Mansell et al 2007); understandings of adults with learning/ intellectual disabilities as sexual human beings also vary across and within European countries (Katalinić et al 2012). Project partners responsible for interviews in their own country were alerted to the need for sensitivity. It was particularly important to be sensitive when interviewing adults with learning/intellectual disabilities and to take account of power relationships, especially where people were living in residential settings and an accessible consent form (with easy words and pictures) was produced which clearly indicated that people could withdraw from the project at any point (this was also emphasised during the interviews). Care was also taken to ensure that adults with learning/intellectual disabilities understood what the project was about and what they were signing when they signed the consent form. Where information was collected about people who were unable consent to participate in research, this data was collected from third parties (for example, parents) and did not identify individuals.

Summary and comparison of findings from each partner country

All of the researchers recorded information on the same template, which made it easier to draw comparisons between different countries. When the research findings from the six countries (Germany, Hungary, Finland, Lithuania, the Netherlands and the UK) were reviewed it quickly became apparent that there are many similarities about the situation of adults with learning/intellectual disabilities in each country. One key point made in every country is that where good sex education is happening it is often due to the decision of one individual, or one organisation to work hard at improving the situation. Several researchers acknowledged that people who were prepared to talk with them about sex education and sexual health were more likely to be people who think sex education is important. Interview data from each country illustrated that people hold very varied opinions about sex education for adults with learning/intellectual disabilities: people in the same country, or even in the same area, held different strong opinions about people with intellectual difficulties having relationships or becoming parents. Abuse appears to be a subject that is not spoken about much in any of the six European countries, although there is some variation in the level of awareness. Each researcher highlighted that people are unlikely to report abuse to the police, or talk to anyone about it, which makes it difficult to report how much abuse is really happening. The quantity and quality of sex education taking place also differs from country to country. However one consistent point made was that sex education is more likely to happen as a reaction to a problem, not as a standard procedure available to everyone.

Having noted these wider similarities we can now consider different aspects of the Country Reports in more detail. These are discussed below under the following headings: *Accommodation and living arrangements; Education; Attitudes towards sexuality; What people want; Examples of current practice.*

Accommodation and living arrangements

To put sex education and services in context it is important to understand the current living arrangements for adults with learning/intellectual disabilities. In both Hungary and Lithuania changes happened after the Second World War. In Hungary the government took on responsibility for setting up homes and country homes and castles were nationalised for this purpose. In Lithuania it also became more common for adults with learning/intellectual disabilities to live together in large homes at this time. In both countries there have now been further changes, and people mainly live with family, or in rehabilitative nursing homes. In Lithuania, if it isn't possible for someone to live with their family they will live in a large home with other people with learning/intellectual disabilities until they are 30, and then move into homes that are largely intended for older people.

In the Netherlands, separate institutions were developed for people 'with mental disabilities' slightly earlier (around 1940); these institutions were often in isolated rural areas. Since the 1980's new institutions have been developed in more residential areas and from 1990 there has been more acceptance that people with intellectual disabilities are full members of society. In Germany most people now live with parents, or in supported accommodation. Previously residential schools and long term accommodation were provided for people with intellectual disabilities. However, until the late 1960's people with intellectual disabilities would usually live in psychiatric hospitals. Hospital-like centres were also home for people in Finland until the late 1950's, when people moved into large institutions. The number of people living in these institutions dropped through the 1980's and since 2000 these centres have closed. Large institutions like this were also the home for many people with learning/intellectual disabilities in the UK until 1971, when people began to be discharged from large institutions. However this was a very slow process because of a lack of funding from central government and it wasn't until the 1990s that mass deinstitutionalisation took place in the UK. Most people now live in smaller group homes or with their families. Some new hospitals were opened for people with 'challenging behaviours' but after high profile reports about abuse at one of these hospitals (Flynn 2012), the UK government has recently made a commitment to move people out of these hospitals by 2014 (DH 2012).

Education

The type of education available to children and people with learning/intellectual disabilities has clear implications for the amount of sex education available. The findings of these reports indicate that legislation and policy concerning the general education of children and young people with learning/ intellectual disabilities differ considerably in different countries. In Hungary, education is compulsory until the age of 20 for all people with intellectual disabilities. In the UK mainstream education is compulsory until the age of 16, and full-time education must also be made available for any children with learning difficulties until they are 18. In Finland mainstream comprehensive schools are required to teach children with 'moderate mental disabilities, or severe mental disabilities'. In the Netherlands education is compulsory for children aged 5 to 16. However, parents can request a child to be exempt from compulsory education if they have physical or mental disabilities, such as severe cognitive learning/intellectual disabilities. Children exempt for this reason usually attend an institution or day centre. In Lithuania the Law states that Education is available (though not compulsory) to all who want or need it. Education is available for all young people with Special Educational Needs in Germany.

It is also important to consider the type of sex education that is available in mainstream schools. The standard of sex education in German schools is slowly improving. In Dutch schools sex education became compulsory in December 2012. This is usually focused on contraception, reproduction and sexually transmitted infections and schools decide the form of the education individually. In the UK basic sex education is compulsory in all schools, and any pupils with learning/intellectual disabilities in mainstream and special schools should be included in sex education. In Finland the hours available for teaching sex education have dropped since the 1990's, although teaching hours for general health education have doubled. In Lithuania and Hungary anyone who is integrated into mainstream schools will get some basic sex education in Biology lessons.

In Hungary, sex education for children is seen as a responsibility for parents, but parents often have little information or knowledge. Sex education isn't seen as important for adults with learning/ intellectual disabilities. Residential homes are responsible for making decisions about how to deal with the issue. The situation in Lithuania is similar. Sex education lessons do not happen in special schools and there is very little sex education for adults, though some social workers or psychiatrists will give support. Individuals may also be taken to a doctor to be provided with more information. In the Netherlands there is no sex education aimed at adults with intellectual disabilities, though it is possible for people to take part in classes in an institution, or training for a particular job. In Germany, there are varied sex education services in different areas of the country, though there is often less available in rural areas.

In Finland and the UK, education opportunities for adults with learning/intellectual disabilities are varied, which can make it hard to establish how much sex education is made available. In Finland 'Vocational Education and Training' (VET) is available to all adults. People with intellectual disabilities sometimes study in specialised centres, or units within mainstream VET centres. Some sex education is available in VET institutions, in further education and in day and work centres, housing units, courses, disability clinics, groups and independently. In the UK some adults with intellectual disabilities study 'Life Skills' courses within Further Education Colleges, or attend Day Centres or Advocacy groups. Some sex education may be provided in any of these settings. In both Finland and the UK, where teaching does happen, it is often focused on talking about what is 'appropriate behaviour'.

Having looked at existing education provision, it is also important to consider the attitudes that are held by various people in each country. Existing policy and legislation can also give an insight into this.

Attitudes towards sexuality

In both the UK and the Netherlands it is legal for a person without disabilities to have sex with someone with disabilities, as long as there is mutual consent. There is a similar law in both these countries to say that any sexual contact between a carer/support worker and person with learning/intellectual disabilities is against the law. In Lithuania, the 2005 Law on Social Integration of Disabled People improved people's rights. People now take part in an assessment of their support needs and ability to work. No laws exist about compulsory sterilisation, or to do with sexual consent. In the UK a Compulsory Sterilisation Bill was debated in 1931, but never became law although women with intellectual disabilities were still illegally sterilised against their will (Tilley et al 2012). People with learning/intellectual disabilities have the right to have relationships, and have children in the UK; however, a high percentage of children with parents with learning/intellectual disabilities are taken into social services care.

In the Netherlands around 5% of people with intellectual disabilities become parents. There is frequent debate about whether people with intellectual disabilities should be allowed to have children. Some people believe there should be a law making birth control compulsory – this was considered in 2005, and 2012 but hasn't been passed. In Finland since 1987 people with intellectual disabilities have had the right to marriage and family. However many people still would not expect people with intellectual disabilities to marry or have children. In Hungary many people hold a similar opinion that people with intellectual disabilities are not seen as capable of taking responsibility for a family. Relationships are allowed, but often only with limited touching; the family of people with learning/intellectual disabilities would have to approve a relationship for it to be allowed.

It is also important to consider the issue of abuse when thinking about sex education. It is difficult to find out about the level of abuse that happens to people with intellectual disabilities because that abuse is often not spoken about, or may be happening to people who find it difficult to communicate. A UK report in 2001 found sexual abuse is four times higher in disabled people than the general population, and people with learning/intellectual disabilities are at the highest risk of abuse. In Finland it is estimated that disabled woman are two to ten times more likely than other women to experience sexual violence. A 2011 report by the Dutch Ministry of Health said sexual abuse happens more often to people with mental disabilities. A 2005 report estimated that 60% of people with mental disabilities have experienced sexual abuse. It is also possible that where more abuse is reported this may be due to more support and awareness, rather than because more abuse is happening than elsewhere. In Hungary there are no laws regarding abuse of people with intellectual disabilities. If abuse is reported to the police the trial procedure can be long, destructive and painful. The UK process has a similar reputation. In Germany care organisations seem to be becoming more aware of the risks of abuse recently.

In addition to considering the current availability of education provision it is important to consider people's feelings about the current provision and what they would like to see in terms of sex education in the future. In order find out about this, interviews were carried out in each country with adults with learning/intellectual disabilities and their parents.

What people want

One noticeable difference between countries was the extent to which people were comfortable talking about these issues. In Hungary, Germany, and the Netherlands, the people with learning/intellectual disabilities who participated in the interviews had a lot of unanswered questions about sex and relationships, and said they would like to know more. Some people felt comfortable sharing these questions with the person that interviewed them. In Lithuania people seemed reluctant to talk about sex, they were embarrassed and didn't know much. In the Netherlands sexuality is also still a taboo subject for many parents, although some become more understanding once spoken to by staff about it.

Both young people and adults with intellectual disabilities in the UK spoke about wanting to know more about sex and relationships. They said that in the past information they were given was hard to understand. Young people who had been given support or education seemed more comfortable talking about sex. In each country different parents held different opinions. Parents in Finland felt sex education needed to be available in different ways and different levels for people with varying levels of understanding. In Lithuania and the UK some parents spoke about needing resources they can use themselves, some want other people to talk to their children, and some think sex education is something their sons/daughters wouldn't understand. In the UK, some parents had hopes that their child would have relationships, but were unsure how likely that was to happen. They also spoke about fears of their children being taken advantage of and some parents in Germany and Hungary had similar hopes and fears.

When staff who were responsible for supporting people with learning/intellectual disabilities in each country were interviewed about sex education, many felt they would need more training or support to be able to give good sex education. In the UK some school staff said more resources would be useful, while others felt it would be more appropriate for sex education to be delivered by someone else. Some care staff in Hungary mentioned lectures about sex education that are aimed at staff or parents but said this information isn't passed onto other staff, or residents. Staff in Lithuania had divided opinions about the importance of sex education. Some said it is necessary, because of how people behave, but felt uncomfortable about delivering it. In the UK, staff explained there can be a conflict of opinions between staff who feel sex education is important, and parents who are concerned about the impact on their child, or see it as unnecessary.

Examples of current practice

Another importatn part of this research was to consider sex education work that is already happening, and to learn from this by looking at examples of good practice in sex educationa and the barriers that people implementing this have have faced. In Lithuania there aren't currently any organisations that specifically deal with sex education for disabled people. Organizations working with people with intellectual disabilities don't have special sex educators, some organisations do have some kind of educators who will talk about sex, such as social workers or psychologists. 'Molnár Gábor Műhely Alapítvány' (MGMA) is an institution in Hungary maintained by civil society that people with learning/ intellectual disabilities can attend daily, which includes development sessions. Staff at MGMA have an open approach to sexuality, this includes allowing residents to have relationships and loving connections. They encourage residents to talk about sexual topics, and give it high importance among other aspects of being an adult. Many development sessions include elements connected to gender, behaviour and hygiene. The institution also runs a club for parents of people with disabilities where sexuality is included as an issue for discussion. The 'Hand in Hand' project, at another institution, delivers some training about sexuality to staff from other institutions; a charge is made for this training.

In Finland, there are two examples of sex education work funded by Finland's Slot Machine Association (RAY). Tampere City Mission manages a development project which aims to support people with learning/intellectual disabilities by giving support around sexual health issues, and providing information about sexuality issues and experiences. The project involves educating professionals in working with clients with disabilities and producing jargon free sexual health information. They have also opened a Sexual Health service point in the centre of Tampere for people with learning/intellectual disabilities. The centre can be visited, and questions can be sent to professionals over the internet. SENSO – the social stories in sexual education and guidance project – uses social stories to facilitate discussion of sexuality-related issues. They aim to increase professionals' knowledge and awareness about sexuality and issues concerning sex education. To do this they provide interactive teaching materials for individual and group work, and establish models for how to teach about certain issues. They are now developing

websites which will have accessible materials, videos and stories, and information for both professionals and people with learning/intellectual disabilities. The project aims to reach hundreds of people through training staff to use materials.

In Germany Pro-Familia – Northrhein Westfalen Province provides sexual counselling for people or couples with intellectual disabilities, their families, their teachers and professional supporters and care teams. They also deliver sex education for groups and single people with learning/intellectual disabilities, and provide support for teaching sex education to school classes. Pro-Familia hold information days or evenings for parents, and consultation hours in institutions, as well as delivering training courses in education centres for professional supporters and supporting organisations who want to develop institutional guidelines.

In the Netherlands, Bosch and Suykerbuyk have been working together for over 20 years. They provide some services which are similar to Pro-Familia such as holding sex education courses for care providers from organisations where people with intellectual disabilities live, work or spend the day. They developed the play/learning materials 'Discover who you are' which organisations purchase to use, and have also developed informative materials and written many books on sexual abuse, sexual development, improper sexual behaviour and other topics. Sensoa and Movisie developed a flag system which aims to prevent, identify and manage sexual health concerns and improper sexual behaviour among young people and adults with learning/intellectual disabilities. The system uses pictures of various behaviours to aid discussion of appropriate behaviour; different flag colours are used to illustrate how acceptable or unacceptable the behaviour may be. Sensoa and Movisie offer training about how to use this system and more than 65 organisations in the Netherlands and Belgium have now taken a course to learn how to work with the flag system.

In the UK, the Pearl Service (based in a Sexual Health Clinic at a hospital in London) makes use of the resources of the mainstream clinic to deliver an easy access service for people with learning/intellectual disabilities. They offer screening for sexually transmitted infections and advice and information around safer sex. Free condoms are available as well as contraceptive services. People with learning/intellectual disabilities can refer themselves or can be referred by GPs, family members, carers or social workers with the client's consent. The Josephine Project uses life-size cloth figures to deliver interactive workshops about issues to do with sexual health and relationships, and practical topics such as pregnancy, periods, cancer. The workshops are used by supported housing and health organisations, advocacy groups and education centres. Women with learning/intellectual disabilities developed the project and now lead the workshops. A men's project has now developed and other organisations are now being trained to deliver workshops themselves.

Conclusion

Although this summary began by highlighting the similarities between different countries, it is clear that there are also differences. Development of living arrangements seems to be moving towards giving people greater independence, but the amount of independence is still very varied from country to country. There are differences in how education is structured, and how adults with learning/intellectual disabilities spend their time. People's expectations about how adults with intellectual disabilities 'should' behave are varied, and this has important implications for any developments in sex education. Conversations with people in each country have illustrated how talking about sex education is more acceptable in some countries than others. The interviews and more detailed descriptions of work that is taking place indicate that there are people in each of the countries who feel there is a need for accessible sex education, and are looking for ways to provide it. There are clear connections between what people have said they would like, and some of the work that is already happening, suggesting there are opportunities to learn from each other.

The next stages of the SEAD project will take forward these connections and opportunities to document good practice examples in sex education for adults with learning/intellectual disabilities, raise awareness of the right of people with learning/intellectual disabilities to be sexual human beings and research the channels through which information about the project can best be communicated.

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