

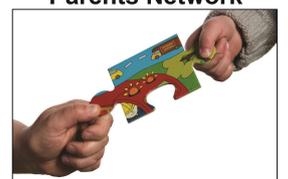
Safe and Healthy Relationships

Empowering & Supporting People with Learning Disabilities through Education

Scottish Commission for Learning Disability

June 2018

Working Together With Parents Network



Introduction

This publication provides some examples of good practice around Relationships, Sexual Health and Parenting Education (RSHPE) for children and young people with learning disabilities, linked to relevant evidence in the literature and some primary research carried out by The Scottish Commission for Learning Disability (SCLD).

Our intention is that it forms the start of an evidence base about what works in terms of promoting safe and healthy relationships which others can build on. It is also designed to initiate a wider conversation about how best people with learning disabilities can be supported and empowered to enjoy safe and healthy relationships.

To do this, the report is comprised of three parts:

- 1.** Compiled responses to a call for evidence and a synthesis of available published work
- 2.** An analysis of a survey that was sent to all secondary schools in Scotland to gather information about their provision of RSHPE for children and young people with learning disabilities
- 3.** A good practice example of work which promotes safe and healthy relationships for people with a learning disability.

Part I - The Published Evidence

A central tenet of Mencap's (2016) 'Relationships and Sex' Vision Statement is the right of people with learning disabilities to form a sexual identity and have a loving relationship. Safe and healthy relationships are the basis of love and offer happiness, fulfilment and companionship. They can also support the social networks which promote our employment, education, housing, family, sexual health and well-being outcomes.

SCLD understands safe and healthy relationships as:

- Having mutual respect for self and others
- Being free of coercion, violence and sexual exploitation
- Engaging in sexual activity that is based on mutual consent
- Being between people who feel good about themselves, share trust and care for each other.

However, a number of barriers can make it harder for people with learning disabilities to exercise this right. People with learning disabilities report they have been denied the ability to make informed choices around relationships, as well as lacking the necessary information to do so (Healy et al. 2009; Wilkinson et al. 2014). Family members, carers and the state can act to restrict personal autonomy and prevailing attitudes still deny the sexuality of people with learning disabilities (Fitzgerald and Withers, 2011). These factors can restrict people with learning disabilities from developing friendships, forming relationships and both having and bringing up their children. Emerson *et al* (2005) conducted a study which found only 3% of people with a learning disability live as a couple, compared to 70% of the general adult population (Mencap, 2016).

People with learning disabilities, therefore, are at risk of lacking meaningful non-professional relationships. They are also at greater risk of sexual violence, discriminatory attitudes and abuse (McCarthy, 2014; McCarthy et al. 2015). Women and girls with a learning disability are even more vulnerable to abuse from partners and are more likely to experience violence from adults who are not their partners, such as other service users, carers, or those who befriend them (McCarthy, 2014; McCarthy et al. 2015). Elderton *et al* (2013) highlight that people with learning disabilities who identify as LGBT are especially vulnerable and are often denied sexual exploration or expression.

From the call for evidence, eight broad themes were established from the literature on safe and healthy relationships:

- Barriers to developing positive sexual identities
- Lack of choice and control

- Restrictions on sexual autonomy
- Vulnerability to abuse and exploitation
- Assessing abuse
- Increasing the scope of and access to sex and relationship education
- Sex education training for staff and social networks
- Peer support

We have chosen to focus on education in this report due to its role in providing the basis for safe and healthy relationships and empowering and supporting individuals to develop them. We look first at some of the key barriers to developing safe and healthy relationships faced by people with learning disabilities, then at how these barriers can be addressed and removed.

Barriers

The term 'eternal children' as applied to people with a learning disability stems from Wolfensberger *et al* (1972) work. Deviance theory is used as a means to explain the stigma of those viewed as different. Wolfensberger *et al* (1972, p.15-16) state:

"It is a well-established fact that a person's behaviour tends to be profoundly affected by the role expectations that are placed upon him. Generally people will play the roles they have been assigned."

Thomas and Wood (2003) argue that treating people as 'eternal children' prevents them from developing separate identities. Wilkinson *et al* (2014) develop this and posit the learning disability identity can become a young person's primary identity and thus become a barrier to the development of a sexual identity. Wilkinson *et al* (2014) go on to identify a number of significant barriers which prevent the development of sexual expression, knowledge and, consequently, the sexual identity in young adults with a learning disability. They argue that these barriers include:

"...carers' views of young people as non-sexual or 'child-like'; the struggle to receive (or in the case of carers, provide) accessible sex education and support; mutual

embarrassment about discussing sexuality; and carers inhibiting sexual exploration in order to manage risk” (Wilkinson et al. 2014, p.99).

Moreover, negative attitudes and stigma associated with the learning disability identity can be internalised by young people and lead to negative attitudes towards their own sexuality (Healy et al. 2009). Being unable to form an identity out with that of learning disability presents a real challenge, particularly with regard to an individual’s sexual understanding. This can be further compounded by the infantilisation of people with learning disabilities.

Jahoda & Pownall’s (2013) study compared the sexual understanding of young people with and without learning disabilities. Their results showed those without learning disabilities had higher levels of knowledge and greater access to larger networks of informal sources of information on sexual development.

Scior (2003) found women with learning disabilities had particularly low levels of sexual knowledge, highlighting the dual disadvantage of this population subgroup. Scior (2003, p.435) provides some evidence of this:

“... on each of the subscales converting Physical Changes that occur at puberty, reproduction contraception, and sexually transmitted infections, the men with LD always achieved higher scores than the women.”

Elderton *et al* (2013) found similar disadvantage amongst people with learning disabilities who identify as LGBT, describing them as a “minority within a minority” (Elderton et al, 2013, p.302). This subgroup experience a double disadvantage which can increase the barriers in forming relationships which are safe, healthy and reciprocal.

Removing barriers

Training for professionals and families

Families, through being overprotective, can add to the societal stigma experienced by people with learning disabilities by denying everyday opportunities to learn

about relationships (Jahoda et al. 2010). Thus the requirement for sex education is not confined to those with a learning disability. Family carers and those with a role in supporting people with learning disabilities also require training to enable people with a learning disability to achieve sexual knowledge and autonomy (Evans et al, 2009). This issue is concisely summarised by Tarnai (2006) who states “*sexual expression is not a problem for people with cognitive disability – but for those who work with them*” (Gomez, 2012, p.238).

Healy *et al* (2009) believe that policy trajectory is now out of step with practice development, and carer attitudes and adequate educational provision lag behind policy intention. This has been compounded by a focus on paid staff training in the prevention of sexually transmitted disease and abuse, whilst limited attention has been given to the provision of training and information for unpaid staff, family carers and individuals themselves. This in turn has led to disempowering attitudes towards the sexuality of people with a learning disability, creating considerable barriers to the sexual empowerment of people with learning disabilities (Evans, et al. 2009).

Evans *et al* (2009) found that just 12% of staff and 8% of family carers had received any training in discussing sexuality with people they support. However, a significantly larger proportion of support workers (53%) had discussed sexuality with individuals compared with family carers (29%). Impediments to support workers discussing sexuality with individuals included:

- a lack of training/qualification (35%)
- a personal lack of confidence in discussing these issues (29%)
- unclear organisational guidelines (16%), and;
- parental wishes (13%)

(Evans et al. 2009).

Support workers may also feel they lack the skills, knowledge or experience to support people who are gay, lesbian or bisexual and there is evidence which suggests some are unable to adopt an open-minded approach to supporting the

sexual identity of the people they work with (Abbot, 2013). Abbott and Howarth (2006) conducted a study with staff and managers of support services across England, Scotland and Wales regarding their views on supporting individuals with learning disabilities to form same sex relationships. A range of key themes emerged from their interviews, which included:

- Support services wanting to ensure those accessing services were in control of their support and therefore not addressing sexuality unless and individual raised it or if a crisis emerged
- Staff lacking skills, confidence and appropriate training to support individuals forming both heterosexual and same sex relationships
- Staff lack of awareness about their organisation policies on sex and sexuality
- Staff struggling to manage concerns from parents and carers.

Evans *et al* (2009) believe it is essential that high quality training is widely available for both paid staff and family carers to minimise personal and individualistic responses to the sexual identity and expression of people with learning disabilities. In doing so, it is hoped sexual autonomy and normalisation for people with a learning disability is achievable.



Provision of Relationships, Sexual Health and Parenting Education (RSHPE)

Sex and relationship education can play a fundamental role in sexual exploration and the subsequent development of a healthy approach to sexuality and relationships. Jahoda and Pownall (2013) highlight that young people with learning disabilities tend to have smaller social networks, relying more on parents for information about sexuality and relationships. Perhaps as a direct result, these individuals also rely on less credible forms of information from the media (Jahoda & Pownall, 2013).

Compounding this, Fitzgerald & Withers (2011) point to a lack of suitable sex education material for people with a learning disability. Healy *et al* (2009) argues that providing tailored sex education to people with a learning disability leads to direct and measurable improvements in individual capacity to make decisions about sexual relationships. In addition, Healy *et al* (2009) suggest that only half of those with a learning disability actually receive sex education. A lack of sex education resources and low levels of sex education among people with learning disabilities leads to low awareness of safe sex practices, contraception, sexually transmitted diseases, sexual consent and abuse (Evans et al, 2009). This viewpoint is furthered by Jahoda and Pownall (2013), who cite Cole & Cole (1993) and consider the impact small social networks coupled with limited peer interaction can have on knowledge gain. Sexual health is often seen as a private area of people's lives and consequently knowledge is often gained through discussions with peers, resulting in limited information transfer for this population sub-group (Jahoda and Pownall, 2013).

Given the complex social nature of the barriers and challenges experienced by people with learning disabilities, it seems one of the most appropriate ways to address these issues is to consider how sex education is taught. Schaafsma *et al* (2014) focus on the value of ensuring sex education for people with learning disability shifts from reactive to proactive and is delivered as a preventative early intervention, rather than as a crisis response. In a 2014 study of unpaid care staff, Schaafsma *et al* (2014) found that sex education was provided reactively, delivered in response to direct questions on sexual conduct or to individuals acting in a sexually inappropriate way. In the same survey, "the client is developmentally ready" was ranked by respondents as the lowest rationale for the provision of sex education (Schaafsma et al. 2014, p.162). Schaafsma *et al* (2014) go on to argue that effective sex education for people with learning disabilities requires:

- The implementation of policy (as much as the policy itself), and
- High quality training courses for staff.

McCarthy (2014) identifies specific requirements of sex education. She highlights the need for a focus on the experience of the female, and suggests that pleasure and enjoyment should be paramount in the experience. Consequently, the education provided should reflect this and women in particular should be empowered to demand an enjoyable experience (McCarthy, 2014). Tepper (2000) argues that failure to promote a positive sexual discourse for women will continue to see them victimised and result in low sexual self-esteem. Bernert and Ogletree (2013, p.126) further this by arguing that negative perceptions of sexual activity and pleasure are still prominent and abstinence is adopted not as a “positive, informed choice” but rather as a way of avoiding risks. Additionally, Fitzgerald & Withers (2013) found that some women with a learning disability did not think of themselves as sexual beings, reflecting the theories around the development of sexual identity. Sex education should help women with a learning disability to better understand risky situations, and to evaluate the motivations of others, such as men who are relative strangers (McCarthy, 2014). In evidencing this, McCarthy (2014) cites Eastgate *et al.* (2011) who assert women with learning disabilities do not usually make the initial advance in a sexual relationship, and that there is often confusion about their right to refuse the sexual advances of others. McCarthy (2014) argues that there is a need to improve the social standing of women with learning disabilities, to show that they are “worthy of respect and protection” (2014, p.5).

Bernert & Ogletree (2013) also stress the importance of sex education, emphasising positive messages that contribute to sexual self-efficacy, self-determinism, and self-advocacy. They believe this is crucial for people with a learning disability to achieve sexual autonomy, privacy and develop healthy relationships. In line with this, an approach to providing sex education in Australia has been developed with people with a learning disability playing an active role as peer educators. The programme is was developed and delivered by people with a learning disability, underpinned by the principle that people with a learning disability are experts in their own lived experience (Northway *et al.*, 2013).

A proactive approach requires improved access to sex education for people with learning disabilities themselves. Consideration must be paid to the benefits of peer delivered sex education which emphasises sexual rights and autonomy, female sexual pleasure and LGBT identities, as well as an awareness of risk.

Part II - Education Survey

Education was an emerging key theme in our evidence gathering. In acknowledgement of this, and based on the above outline of the barriers which individuals with learning disabilities face in the formation of positive sexual identities, SCLD wanted to examine the provision of RSHPE for individuals with learning disabilities in Scotland. In line with the current work programme, SCLD had a particular interest in the information provided in education programmes about becoming a parent.

Parents with learning disabilities often face significant barriers as a result of professional concerns for the well-being of their children (Tarleton 2014). Stewart *et al.* (2016) identified that early intervention allowed for a strength-based approach to be used to help individuals with learning disabilities develop their parenting skills. Parenting education, as part of RSHPE, can be identified as an important part of what we understand as early intervention and support.

To develop an increased understanding of RSHPE provision, SCLD sent a survey to all secondary schools in Scotland¹. A national approach was taken due to the absence of a readily available list of Additional Support Needs (ASN) Schools and Schools with Additional Support Needs bases or units. Whilst the list of schools in Scotland identifies ASN Schools, it does not identify schools with an ASN base or units.



¹ Contact list available from here: <http://www.gov.scot/Topics/Statistics/Browse/School-Education/Datasets/contactdetails>

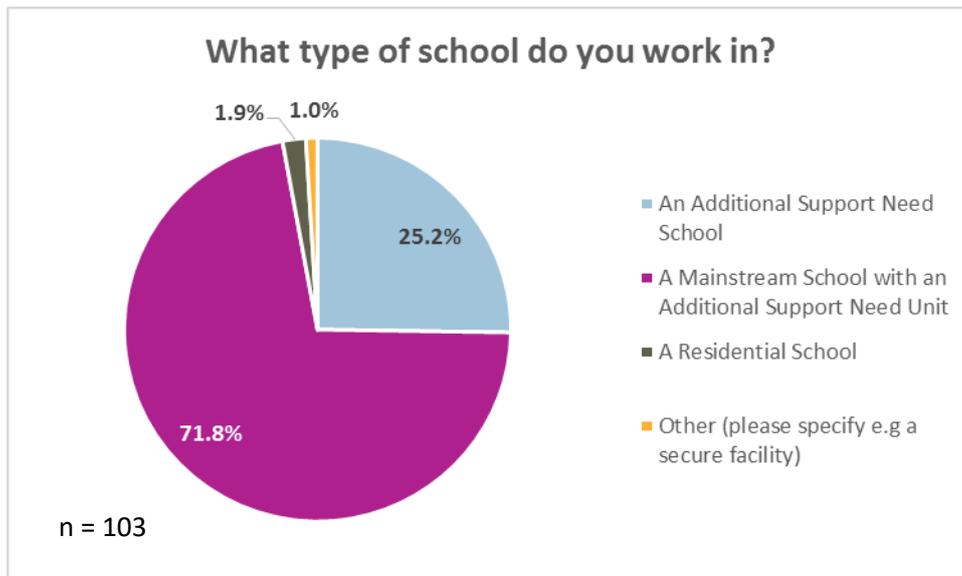
The narrative accompanying the survey contained an instruction to non-ASN schools and schools without an ASN base or unit not to respond to the survey. However, a small number of schools without an ASN base, who were providing an ASN style service, responded. This means there are potentially other schools without an ASN base who provide an ASN style service who did not respond.

There were 130 responses in total. Questions were not mandatory and a number of respondents chose not to answer various questions. As a result, the total number of responses to each question varies. The base referred to is made clear in the diagrams below.

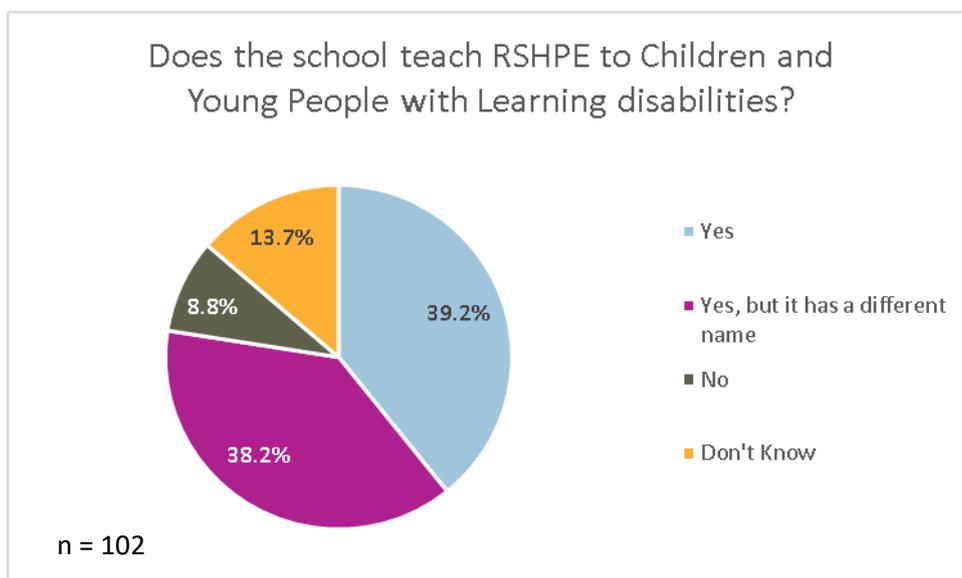
Key survey questions asked respondents to discuss:

- The type of RSHPE provided to young people
- Whether information about pregnancy was provided to young people with learning disabilities
- Whether assessments of individuals' knowledge and understanding were made or provision was evaluated
- The barriers in providing RSHPE to young people with learning disabilities
- The changes required to RSHPE to better meet the needs of individuals with learning disabilities

A descriptive analysis of responses is outlined below.

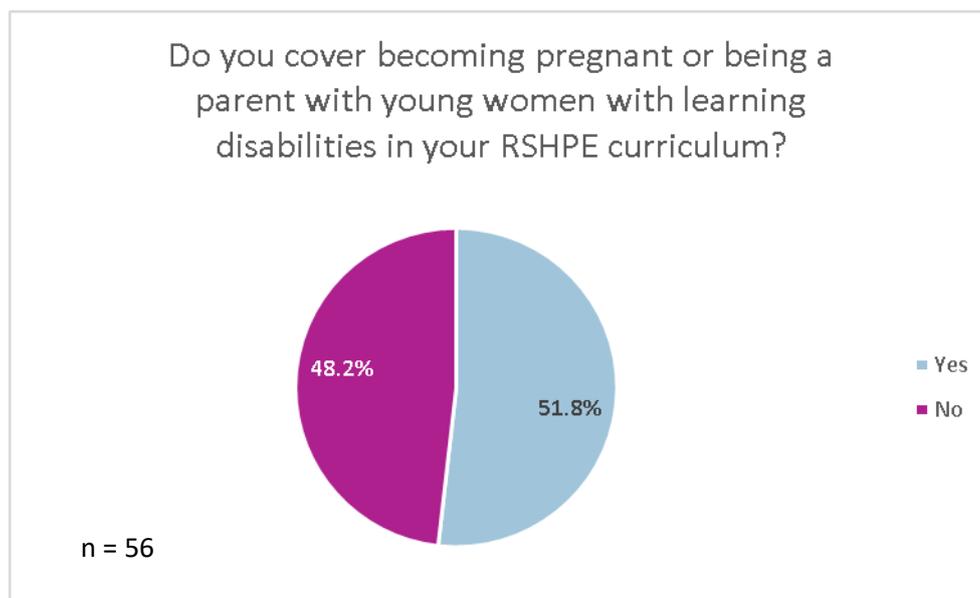


Over two-thirds (71.8%) of respondents worked in a Mainstream School with an Additional Support Need Unit. A further quarter (25.2%) worked in an Additional Support Need School. 1.9% of respondents worked in a Residential School and 1.0% worked somewhere not listed as an option; a Special School for pupils with emotional and social difficulties.



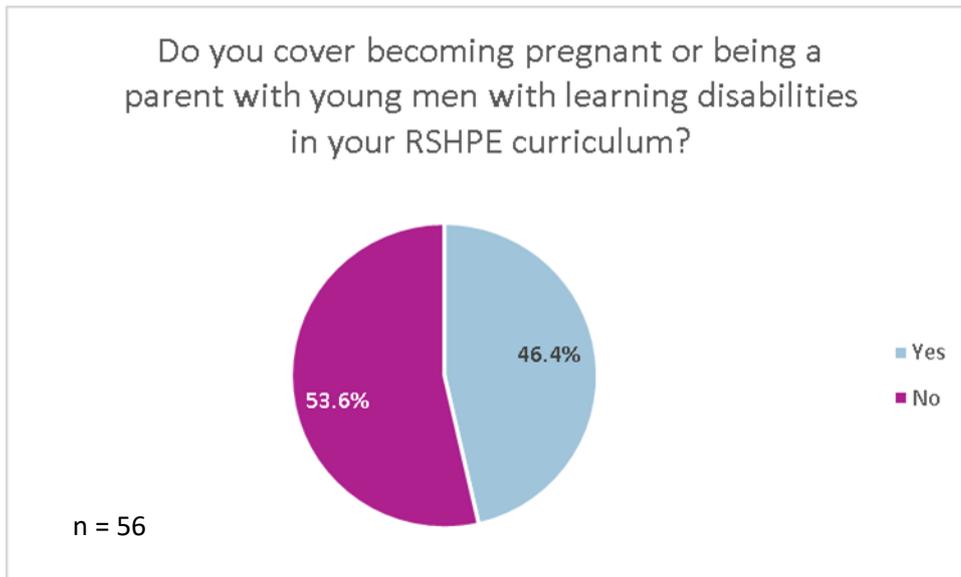
Over a third (39.2%) of respondents stated their school taught RSHPE to children and young people with learning disabilities. A further 38.2% said they taught RSHPE to children and young people with learning disabilities but it had a different name,

such as Personal and Social Education (PSE), Personal, Social and Health Education (PSHE), SHARE, Sexplanation, Keeping Myself Safe and Called to Love. In total, over three quarters (77.4%) of respondents worked in schools that teach RSHPE to children and young people with learning disabilities. 8.8% of respondents stated that their school did not teach RSHPE to children and young people with learning disabilities while 13.7% stated that they were unsure about the RSHPE provision where they worked.



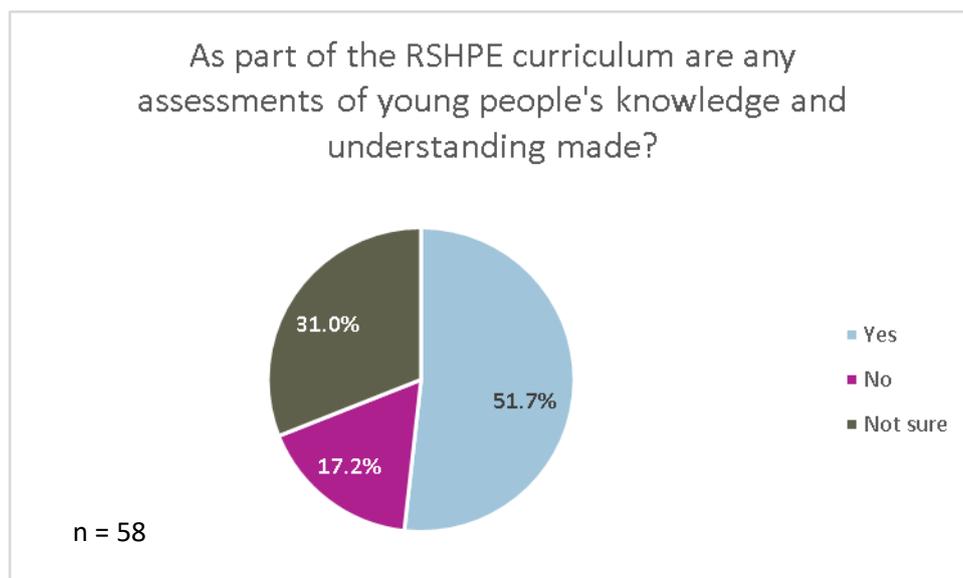
Just over half (51.8%) of respondents stated they covered becoming pregnant or being a parent with young women with learning disabilities in their RSHPE curriculum.

Respondents answering 'yes' to this question were then given the opportunity to detail the type of information taught in these sessions. The responses given included: getting pregnant, the stages of pregnancy, contraception, parenting skills (including budgeting), menstruation, relationships, abortion, choices, and consent.



Less than half (46.4%) stated that they covered pregnancy or being a parent with young men with learning disabilities in their RSHPE curriculum.

Respondents answering 'yes' to this question were then given the opportunity to detail the type of information that was taught in these sessions. The responses given included: getting pregnant, stages of pregnancy, contraception, parenting skills (including budgeting), sexual health, consent, and responsibility.



Over half (51.7%) of respondents said assessments were made of young people’s knowledge and understanding as part of the RSHPE curriculum. A further 17.2% did not carry out assessments of young people’s knowledge and understanding.

Respondents answering ‘yes’ to this question were then given the opportunity to detail the type of assessment that was used to determine young people’s knowledge and understanding. A variety of methods were described. We have grouped them as follows:

- **Formal assessments:**

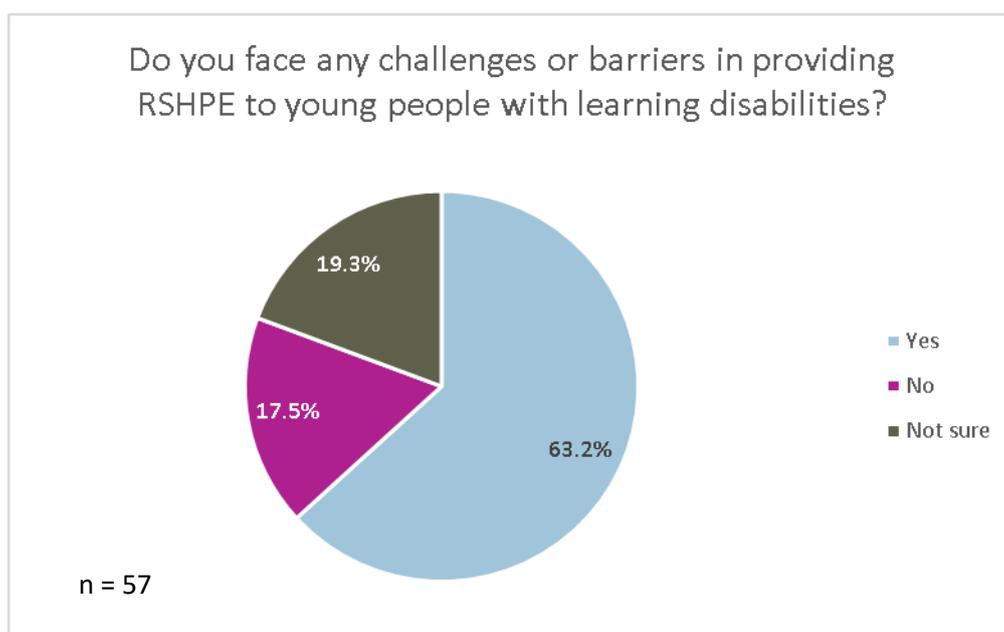
Formal assessments included: written work assessments, questionnaires, evaluations, and pupils delivering presentations.

- **Informal assessments:**

Informal assessments included: discussions, pupils being questioned, role-play, teacher observations, self-assessment and peer assessment

- **Specialist assessments:**

Specialist assessments included: Community Health Disability Nurse or School Nurse assessments for pupils who have complex support needs or are displaying concerning behaviours.



Nearly two-thirds (63.2%) of respondents reported facing challenges or barriers in providing RSHPE to young people with learning disabilities.

Respondents answering 'yes' to this question were asked to specify the barriers they encountered. Some key themes emerged:

- **Resource issues:**

Resource issues included: mainstream materials needing adapted, difficulty in getting resources and having the appropriate resources and assessment material

- **Staff issues:**

Staff issues included: lack of training and lack of time

- **Class setting issues:**

Class setting issues included: mainstream schools and classes are too fast paced for young people with learning disabilities, working in a small mixed ability, gender and age range class means it is difficult to find topics and materials that are appropriate for everyone.

- **Parental issues:**

Parental issues included: reluctance for their child to be taught RSHPE, concerns that teaching their children can 'plant seeds' about sexual activity and parents requesting that their child is not taught RSHPE

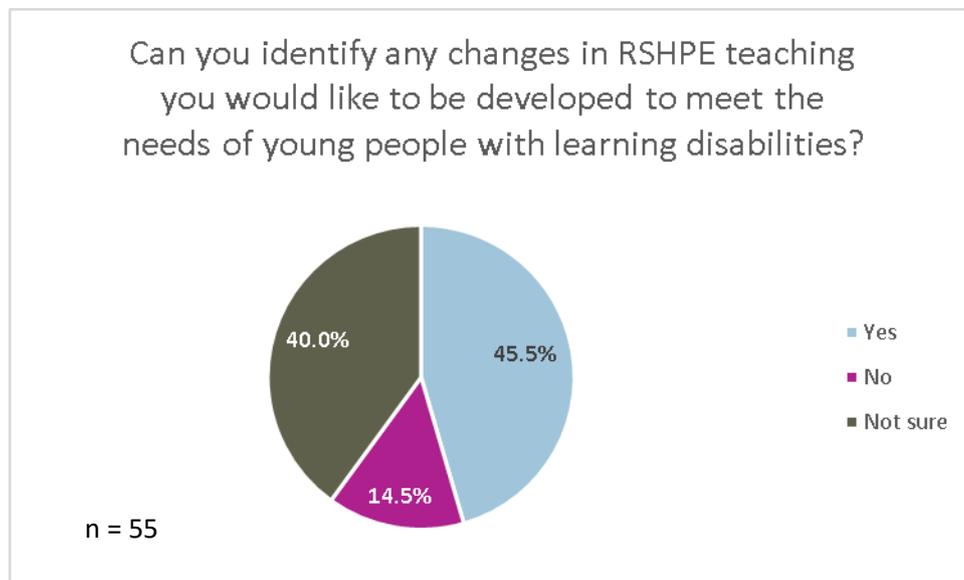
- **Pupil issues:**

Pupil issues included: retention of information, issues with knowledge and understanding and issues with willingness to take part

- **Health professional issues:**

Health professional issues included: an unwillingness from health professionals to visit classrooms both for the purposes of knowledge building but also building

positive relationships between young people with learning disabilities and health professionals.



Almost half (45.5%) of respondents could identify changes in RSHPE teaching they felt could be developed to better meet the needs of young people with learning disabilities. A similar proportion (40%) were not sure if they could identify any changes necessary in RSHPE teaching.

Respondents answering 'yes' to this question were asked to detail the changes they would like to see. We have grouped these as follows:

- **Resources:**

Resource developments suggested included: more resources in an accessible format, more specific ASN resources, more up-to-date resources and information, more focus on pregnancy and becoming a parent and nationally adapted materials that would be available from a recognised source

- **Staff:**

Staff developments suggested included: more staff training and generally more staff

- **Health professionals:**

Health professional developments suggested included: more support from experts, visits from health professionals to discuss contraception and self-examination for breast and testicular cancers and more partnership working with health professionals.

Part III - Case Study

SCLD wanted to illustrate the survey findings with a case study of local practice. The following highlights one school's journey to improving RSHPE for children and young people with learning disabilities.



Carronrange is an Additional Support Needs (ASN) school in Falkirk.

Carronrange School

Following new appointments in Carronrange School, the existing RSHPE resources were reviewed. They were found to be outdated and lacking in diversity with an absence of information on couples who were same sex, of a range of ethnic origins and/or who have learning disabilities. It was also discovered that SHARE (Sexual Health and Relationships Education) was being implemented by a minority of teachers to sixth year pupils, while education to other year groups was limited to basic hygiene and friendships. Other education provided on this subject appeared to be delivered as a crisis intervention following inappropriate sexualised behaviour.

To support the development of a new RSHPE course, staff attended a range of relevant training and conferences. From this, partnership work was developed through the formation of a group of likeminded professionals. This group included NHS Forth Valley, Community Sexual Health Educators (CSHE), teaching staff, and support for learning assistants, pupils and a Makaton co-ordinator. The new RSHPE course aimed to reflect current legislation and policies and include examples of good practice. Central to the training was the need to provide teaching staff with the skills and confidence to deliver the programme.

The new RSHPE outline drew on a range of materials and resources from a variety of organisations including Central Sexual Health, NHS Lothian, Sandyford and the NSPCC. Once developed, the course was then trialled and pupils were interviewed about their opinions on the content and delivery. These comments were incorporated into the development of the course before it was then unveiled to the wider staff group.

The Carrongrange RSHPE course ranges from S1 to S6 and covers a number of topics, including healthy relationships, masturbation, pornography, abuse, exploitation and starting a family. Presently the population of the school is predominantly male and comprised of approximately 80% students with moderate learning disabilities and 20% students with multiple and complex learning disabilities. Classes are mixed gender aside from S1 puberty classes which have been separated at the request of the students.

The impact of the courses are measured by video diaries, photographs, discussions with the students and informal assessments. Comments from pupils who have been through the twelve week programme said the course had “been helpful”, “informative”, that they “got advice”, and it “taught me stuff I didn’t know”, as well as reinforcing knowledge they already had.

“I’ve learned about abuse and that and what abuse is and a little bit about HIV and that.”

“How to use protection if you’re going to have sex. How to actually be in a relationship. About abuse and how to avoid getting an STD. How other people work and that.”

These comments are in contrast with remarks from outgoing sixth years, who stated that they had not had any information about abuse and healthy/unhealthy relationships and had received very little RSHPE teaching in general.

Carronrange S1 Relationships, Sexual Health and Parenthood Programme

Lessons	Experiences & Outcomes	Success Criteria	Suggested Resources
Lesson 1. All About Me	<p>I am aware of and able to express my feelings and am developing the ability to talk about them. HWB 0-0fa/ HWB 1-0fa/HWB 2-0ta/ HWB 3-01a/ HWB 4-0fa</p> <p>I recognise that each individual has a unique blend of abilities and needs. I contribute to making my school community one which values individuals equally and is a welcoming place for all. HWB 0-10a / HWB 1-10a / HWB 2-10a / HWB 3-10a/ HWB 4-10a</p>	<p>I can list my own skills and qualities</p> <p>I can explain what makes me a good friend</p>	<p>Personal Details Worksheet My Favourite Things Likes and Dislikes Worksheet Class Bingo</p>
Lesson 2. Decision Making	<p>I reflect on how my attitudes, beliefs, values and morality can influence my decisions about friendships and sexual behaviour. HWB 3-46a/HWB 4-46a</p>	<p>I can demonstrate saying 'yes' to things I like or am comfortable with</p> <p>I can demonstrate saying 'no' to things I do not want or something I dislike.</p>	<p>ASN Booklet pp. 12-15.</p>

Conclusion

People with learning disabilities can face challenges in forming and expressing a sexual identity. Significant barriers to this include societal perceptions of people with learning disabilities, and the impact of multiple disadvantages with regard to gender, sexuality and disability.

These barriers must be addressed for people with learning disabilities to develop safe and healthy relationships. This can be done through the provision of appropriate training for professionals and families providing support in home settings. However, the provision of accessible and outcomes focused RSHPE throughout school life is critical. By providing comprehensive training and education designed to remove these barriers, steps can be taken towards addressing inequality to enable young people with learning disabilities to make fully informed choices about forming relationships and having a family.

The role that education, and particularly RSHPE, plays in the removal of these barriers is significant. The responses to our survey show that RSHPE or PSE was, in the majority of cases, provided to children and young people with learning disabilities across both mainstream and specialist settings. However, significant gaps in education for both young women and men with learning disabilities in relation to pregnancy and becoming a parent were demonstrated.

Furthermore, nearly two-thirds of survey respondents stated they faced barriers and challenges in providing suitable RSHPE including:

- Accessing appropriate and adapted teaching materials
- Teaching in mixed ability classes
- Parental concerns
- The prior knowledge, understanding, and engagement of pupils
- Establishing partnerships between health professionals and schools.

In considering these challenges, almost half of the survey respondents could identify practice level developments which included:

- Providing accessible and up to date resources, availability of teaching materials with a focus on pregnancy and parenting and RSHPE materials produced by a recognised source
- Addressing the training needs of staff and workforce expansion
- Increasing support and partnership work with experts in RSHPE.

The partnership work demonstrated by Carrongrange School, NHS Forth Valley and others highlights opportunities for developing adapted and specialised materials for the RSHPE Curriculum. However, staff having access to resources, training and time to develop new materials was critical.

At the time of this publication, work is ongoing to develop RSHPE provision within the Curriculum for Excellence, across mainstream and specialist settings for children and young people aged 3 to 18. This work will be completed and published in the summer of 2019. Information and the opportunity to inform practice can be found [here](#).

Forming and enjoying relationships, with opportunities to start a family, are key to individuals' social experience. Without opportunities to do this, people with learning disabilities will be at increased risk of living a socially isolated life, excluded from the experiences others may take for granted. The removal of barriers through the provision of training and education can play a vital role in supporting young people to express their sexual identity and develop loving relationships.

Education is a critical part of a wide ranging landscape with regard to ensuring individuals with learning disabilities have the opportunity to form and enjoy safe and healthy relationships. It is SCLD's hope that this document will prompt further conversations about how individuals with learning disabilities can be empowered and supported in safe and healthy relationships, and to experience love.

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