

Learning Disability Sexual Health Needs Assessment 2016-2017

Part 1

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Solent NHS Trust Sexual Health Service was commissioned by the Public Health Team at Hampshire County Council to undertake a sexual health needs assessment of adults with Learning Disabilities.

Overview

As a service we strive to deliver equitable sexual health care to all sexually active patients. This may include clinical interventions in a clinical or outreach setting, behaviour change interventions, education and empowerment through one to one work and small group interventions including in a range of Outreach settings.

The Department of Health (2001) Valuing People: A new strategy for learning disability for 21st century states that *'People with learning disability may have limited access to mainstream health services, and sexual health and genitourinary medicine services are no exception (DOH, 2001;1998). They are often excluded from society, either because they are 'segregated' within specialist support services in the community or because they live in isolation with carers, and health and social care models do not always join up locally to meet their needs'*. Between October 2016 and February 2017 a sexual health needs assessment of parents/carers of people with a learning disability were undertaken. It was decided with our Commissioners that we would conduct sexual health needs assessment in two parts over two years. In the first year we would look at this from the parents/carers view point and the second would be from the LD Adults view point.

Our Needs Assessment took the form of a questionnaire to assess the confidence, training, risk awareness of parents/carers of people living with Learning Disability (PLWLD) knowledge of local sexual health services. We decided to survey Parent and Carers of people living with a LD because it is likely that they will be hugely influential in information sharing and a first Port of Call for advice and if things go wrong and will often be needed for transport to clinic or GP. This survey was completed by (35) people across Hampshire.

This Needs Assessment is the First part of two, looking at what the Relationships and Sex Education (RSE) and Training needs of the Parents, Carers and professionals working with PLWLD (People Living with Learning a Learning Disability. Part 2 will focus on the RSE needs of PLWLD across Hampshire.

Prior to the Questionnaire being distributed a Literature search was undertaken, for previously published sexual health assessments of people with Learning Disabilities in England, which yielded few results.

Background

It is widely acknowledged that there are inconsistencies in the definitions of Learning Disability, there is also no central register of People Living with Learning Disability(PWLD) across health and social care. However, there is a GP Learning Disability register within the Quality Outcome Framework (QoF), but this is widely acknowledged to under estimate the number of PWLD. There are an estimated 1.5 million people in the UK live with a Learning Disability and it is estimated that in England in 2011 1,191,000 have a Learning Disability. This includes 905,000 adults aged 18+ (530,000 men and 375,377 women) source: people with learning disabilities in England 2011 (Public Health England 2011). Emerson et al estimates that there are approximately 25,500 PWLD in Hampshire in 2017 (Emerson et al. 2016). However, we do know that there are a significant number of adults living with a Learning Disability in Hampshire and we can presume that a large percentage of these people will be sexually active or would like to be sexually active if given the opportunity. The majority of adults with learning Disability will be living independently in their own homes, while some will be cared for by parents or living in local authority or in the independent sector care homes and most will be accessing support services. Therefore a key challenge is in educating parents and carers to meet the sex and relationship educational needs of people living with a learning disability when they may not have received a comprehensive sex and relationship education themselves or for them to acknowledge that there is a need for this education.

Previous research has identified that people with a learning disability (LD) are at higher risk of sexual exploitation. This is mainly due to: lower levels of educational attainment, communication barriers, low self-esteem, inability to understand when they are potentially in dangerous exploitive situations, issues around consent (lack of understanding about consent/ capacity to consent, lack of ability or knowledge to report an offence or recognise if an offence has taken place (Brown et al 1995, Franklin et al 2015).

There are findings of a 3 year project by the Centre for Disability Studies at the University of Leeds (Garbutt 2009) to examine the sexual experiences and understanding of people with LD and education. The project explored issues around sex and relationships through group sessions, role play and improvised drama for young people with LD as well as interviews with parents and teachers and a national survey of special schools. The project revealed that while some young people with LD had some knowledge of sex, they also had some serious misunderstandings:

- Several of the young people thought that gay sex was illegal

- In contrast, several didn't realise that the police investigate cases of sexual abuse
- Others were unaware that sex could lead to pregnancy
- Some had little or no understanding of contraception
- Few knew that pregnancy would last 9 months

There is evidence that people with a LD are less likely to have received comprehensive SRE (Sex and Relationship Education) because no national organisation is responsible for delivering it to adults with a learning/intellectual disability; this means that the amount of education and support available varies a great deal in different areas. In some areas Community Learning Disability nurses will support people to gain knowledge, yet in other areas there is no-one in this role. Also the move towards independent living is progressing at different rates in different areas, and the provision of support around relationships may have links to this. Any sex education that does happen takes place in a variety of settings. Life Skills courses in Further Education Colleges may include this. Some sexual health clinics do Outreach work aimed at people with learning/intellectual disabilities. There are some organisations that deliver sex education to groups of adults, such as The Josephine Project, which has gained international recognition and Tina Training (www.tinatraining.co.uk), (https://www.sead-project.eu/wp-content/uploads/2013/10/contryreport_uk.pdf)

This research arose from the increasing number of referrals for clinical intervention in training and education of appropriate social and sexual behaviour in people with moderate to SLD. What became apparent was the lack of suitable materials and assessments, which is significant as a large number of persons with SLD have problems with language, and require tools and programmes which have enhanced levels of pictorial support. An extensive review of the literature revealed that the research on sexuality in SLD was limited. Furthermore research into the development and validation of assessment tools and training programmes which increase appropriate sexual behaviours is urgently required. (Grieveo et al 2007).

We also know that the Family Planning Association (FPA) sexual health charity delivers [a training programme to support adults and young people with LD](#) and the professionals who support them. The current programme is in partnership with Westminster City Council. A Needs Assessment from Northern Ireland was found in 2014 (FPA in Northern Ireland, in partnership with the School of Nursing at the University of Ulster, began a three year research project into the sexual health and wellbeing of people with learning disabilities living in Northern Ireland. The aim was to produce a profile of the feelings, attitudes and experiences of people with learning disabilities in relation to sex, sexuality and personal relationships; and to obtain comparable data from their Carers, formal and informal. This report can be found in the Appendix.

We know from our survey that parents/carers struggle with teaching and discussing SRE with their children and this becomes more difficult for the parents of a young person with LD due to issues with communication, lack of knowledge and information. It is reported that parents/carers don't know where to go for support or guidance. If any questions arise parents/carers tend to go to their Day Services or keyworker who is working with their child or client to ask how to deal with the situation. We discovered that [Scope have training courses for parents/carers](#).

Hampshire County Council published a [Learning Disability Plan for Hampshire](#) in 2016. This plan has been written by the Hampshire Learning Disability Partnership Board. The Board is made up of the following members: 10 adults with learning disabilities, 5 parent/carers, 1 representative from adult services and 1 NHS representative. In Chapter 6 of the plan is focused on Relationships and Family (sited below) and the rights of People with a learning disability to be able to have friendships, relationships and their own families, like everyone else.

Being lesbian, gay or bisexual in a largely heterosexual environment can present many challenges. This can be even more challenging for LGBT people who also have a learning disability. While there is no evidence that people with a learning Disability are more likely to be LGBT, there is evidence to suggest that men with LD are more likely to find sexual partners who are male rather than female—simply because the opportunities present themselves more readily. The fear of a woman with LD becoming pregnant often results in stricter rules around contact between opposite sexes, where it is common for men to share bedrooms and toilets. *‘The sexual experiences of people with LD should inform the baseline to safer sex education work and support aimed at empowering this group to develop positive sexual identities and safer behaviours’* (Johnson et al, 2002)

In recognition of the work that needs to be done around enabling PWLD to have quality relationships and sexual experiences HCC Adults’ Health and Care have developed a Relationship & Sexuality Policy with an Adult Sexual Exploitation Strategy, operational guidance and Risk Assessment Conversation Tool which can be found in the [Appendix](#).

One of the greatest challenges is to bridge the sexual health gap between mainstream sexual health promotion activities and local Sexual Health Services, on the one hand, and a specialist sex education and sexual health work in learning disabilities, on the other. Both need to be integrated at a local level. Following closer working with our Learning Disability Health Colleagues we know that some changes are happening i.e. Health Passports and Permissions to share Documents where the LD person has already given permission to share and documents signed this has been done in collaboration with their GP, therefore linking in with Primary Care. This has made for more effective care in specialist LD Sexual health Clinics, known as SHIELD clinics with Solent Sexual Health Service

More radical approaches include introducing gay advocates or outreach workers for men with LD who have sex with men, education for women who sell sex, and targeted sexual health projects. Developing wider networks of support in the community will also promote the sexual health of people with LD, their social inclusion and sexual rights (Johnson et al 2002).

Specialist sexual health clinics for people living with a learning disability, known as SHIELD (Sexual Health Information Education Learning Disability) Clinics, were developed in Hampshire, Portsmouth and Southampton in 2016 in response to noticeable increases in STIs in adults with a Learning Disability in Portsmouth and SE Hampshire and increasing attendances at mainstream sexual health services by adults with a Learning Disability. The aim of the Shield clinics is to provide a service for people with a Learning Disability at a designated time with a named nurse with a special interest in this field and a named sexual health practitioner. This is an appointment clinic and the patient would be seen at the appointment time, they would be expected, they would not have to wait more than a few minutes in the waiting area, this would mean their levels of anxiety would be reduced and their

Key worker/ carer would not be kept waiting any longer than the arranged and agreed time. The patient would then be seen by a nurse and maybe a Dr if necessary in a 30 minute appointment they would then be seen by the sexual health practitioner and this would ensure that they have understood everything that has happened and nurse/ practitioner would have the time to answer all their questions in a way that they would understand. Permission to share information documents would have already been signed and a Health passport completed if appropriate. All information would be given in easier to read/ understand formats.

Methodology

The team developed a questionnaire to provide a better understanding of the needs of parents, carers and health professionals in relation to SRE for young people and adults with LD in order to reduce the risk of sexual exploitation, unplanned pregnancy and sexually transmitted infections.

Following a quick pilot survey to find out how people would like to receive this it became obvious that it would only be completed with a face to face interaction and that it probably wouldn't be completed on line as professionals have many other questionnaires sent to them and state that they don't have the time or forget. Others asked don't have the facility or the knowledge. However, given a hard copy at a training venue or meeting some were happy to complete it, which in part explains the poor return rate.

The aim of the survey was to establish the confidence and competence of the Parents/Carers to discuss Sex and Relationships with the people with Learning Disabilities in their care. The main theme that the questionnaire covered was around the respondent's knowledge of SRE specifically related to people with LD.

We intent to measure the following variables:

1. To establish our sample characteristics, we asked the following:

- What relationship are you to the Person with LD?
- In which area to you work with these people?
- What age range do you work with?
- What gender are they?

2. To establish if SRE training was needed and how it should be delivered?

- Do you feel confident and competent discussing Sex and Relationship Education (SRE) with the people you support?
- Do you feel able to identify risk taking behaviours exhibited by the people you support?
- Would you know how to access Sexual Health services and /or sexual health information for the people that you support?
- Have you attended SRE training?
- How would you like to receive SRE training?

Followed by additional comments which fell into themes

- Special clinics
- Outreach staff
- Tailor made resources appropriate to the needs of the client
- Specific training for those on the autistic spectrum

In total, 35 people responded to our survey, however, and not all answered every question.

1. Question asked 'What relationship are you with the person with a Learning Disability
2. In which area do you work with these people?
3. What age range do you work with?
4. What gender are they?

A copy of the questionnaire is included at Appendix.

Results

Sample characteristics

35 people completed the questionnaire -

Carer- 8

Parent – 5

Volunteer -3

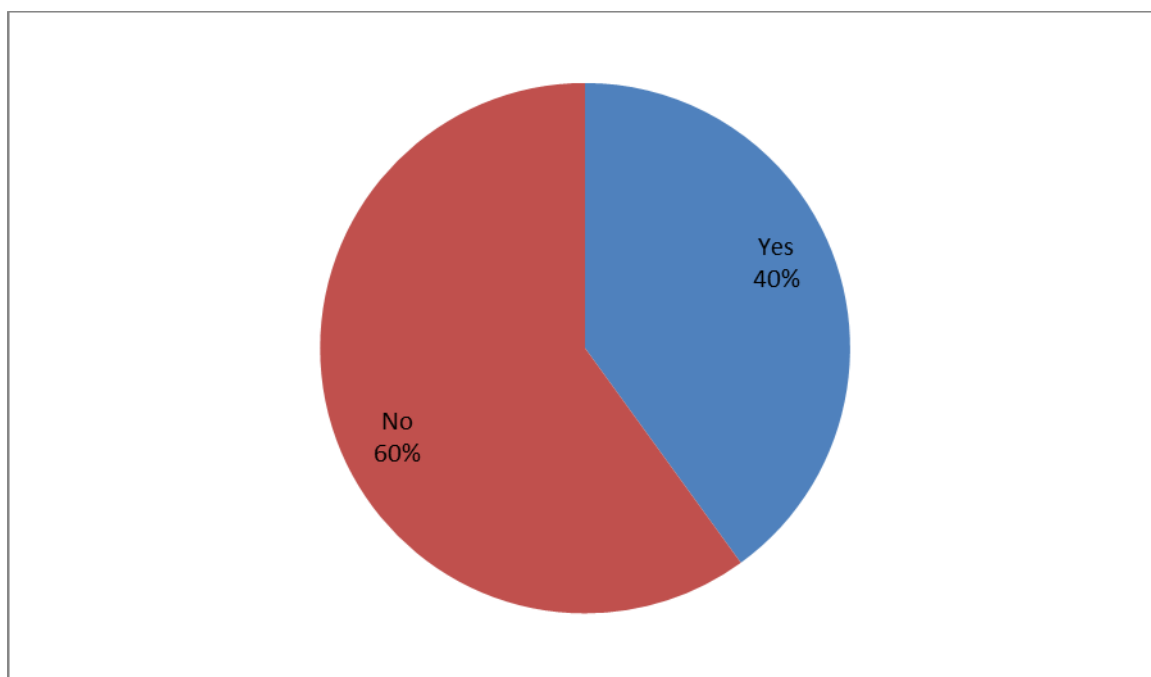
Professional -19

Overarching Themes

The needs analysis although low in number and, and low participation rate there were significant themes

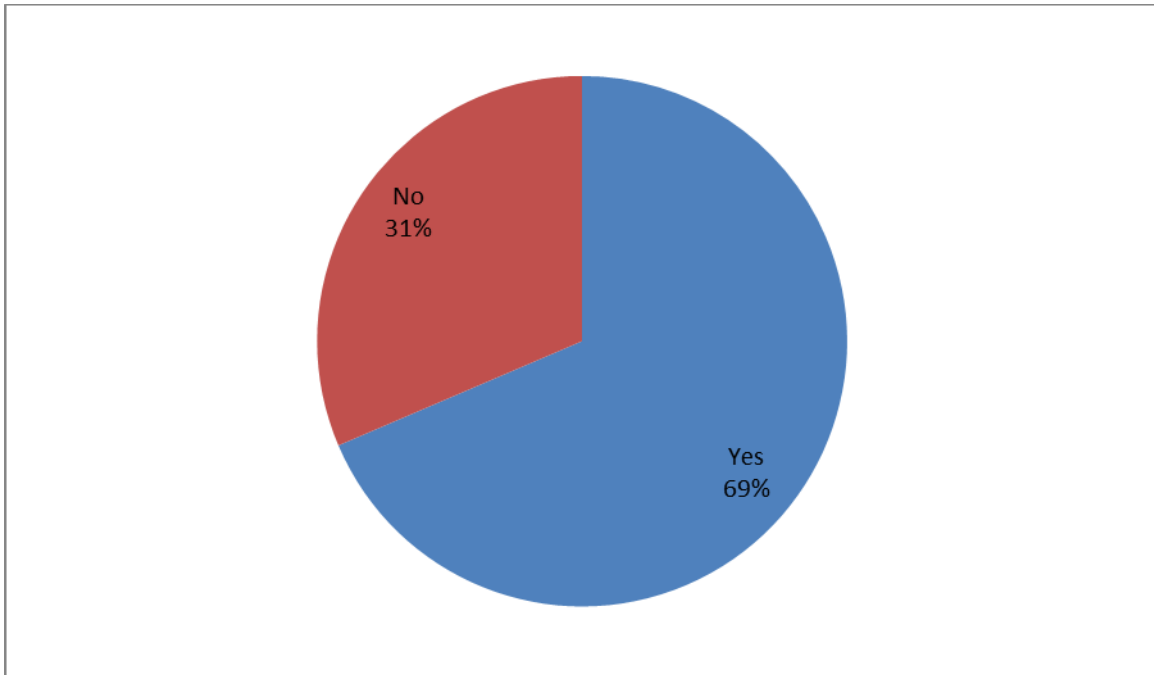
- 40% of respondents felt confident when talking about SRE
- 69% felt able to identify risk taking behaviours
- 82% would know how to access a sexual health service or sexual health information
- 26% had had SRE training
- 53% would like to access training by going on a Course, 26% would like to receive an SRE recourse pack, 14.3% would like to do a Web based course and 4.7% would be happy with any course.

1. Do you feel confident and competent discussing Sex and Relationships Education (SRE) with the people you support?



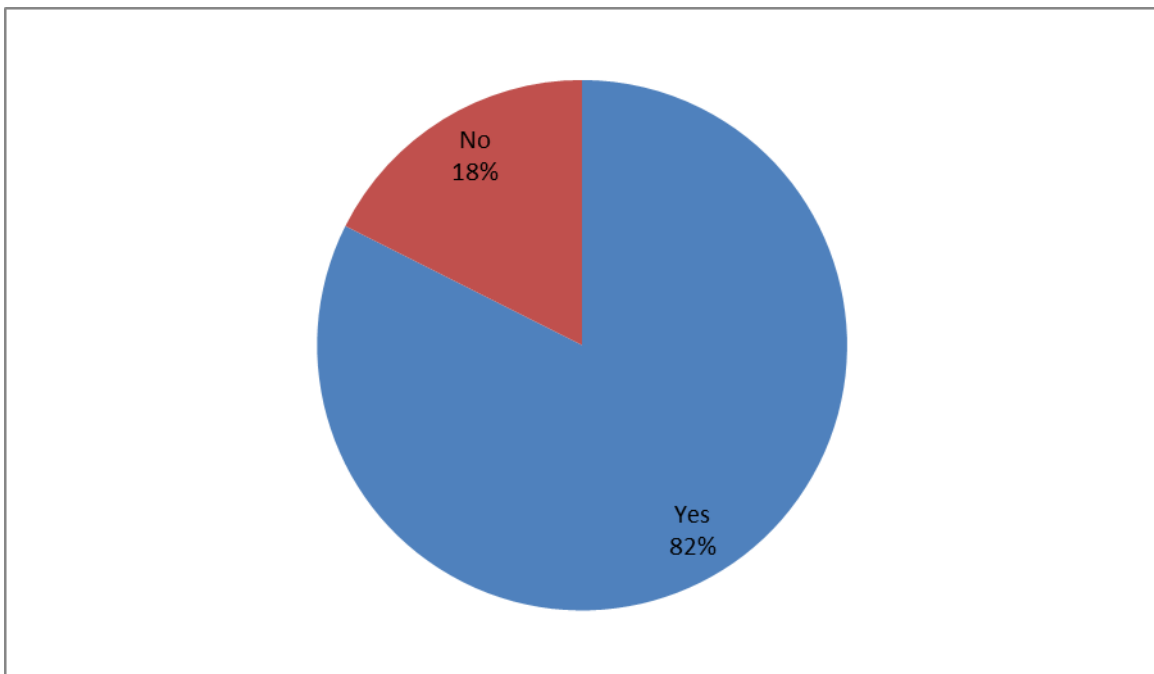
The majority of respondents did not feel confident and competent to discuss sex and relationships with the people that they were caring for and this also showed no difference between parents/carers or professionals

2. Do you feel able to identify risk taking behaviours exhibited by the people you support?



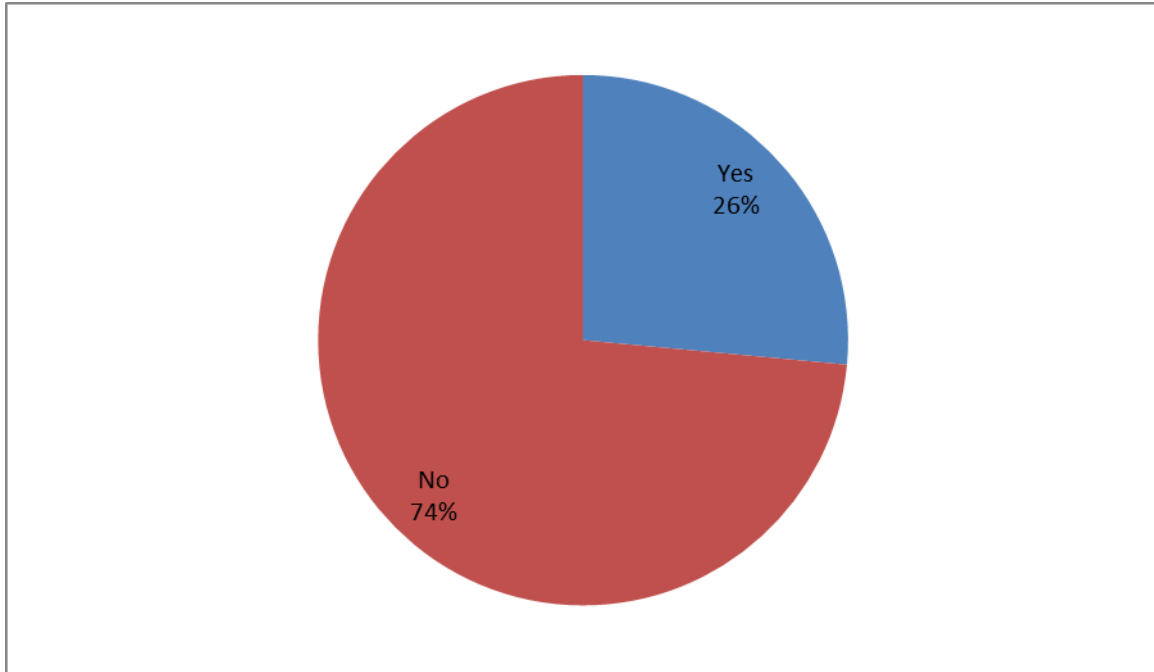
The majority of respondents did feel able to identify risk taking behaviours, more professionals including carers felt able to do this than parents.....

3. Would you know how to access Sexual Health services and/or sexual health information for the people you support?



The majority of respondents did know how to access to access Sexual health Services

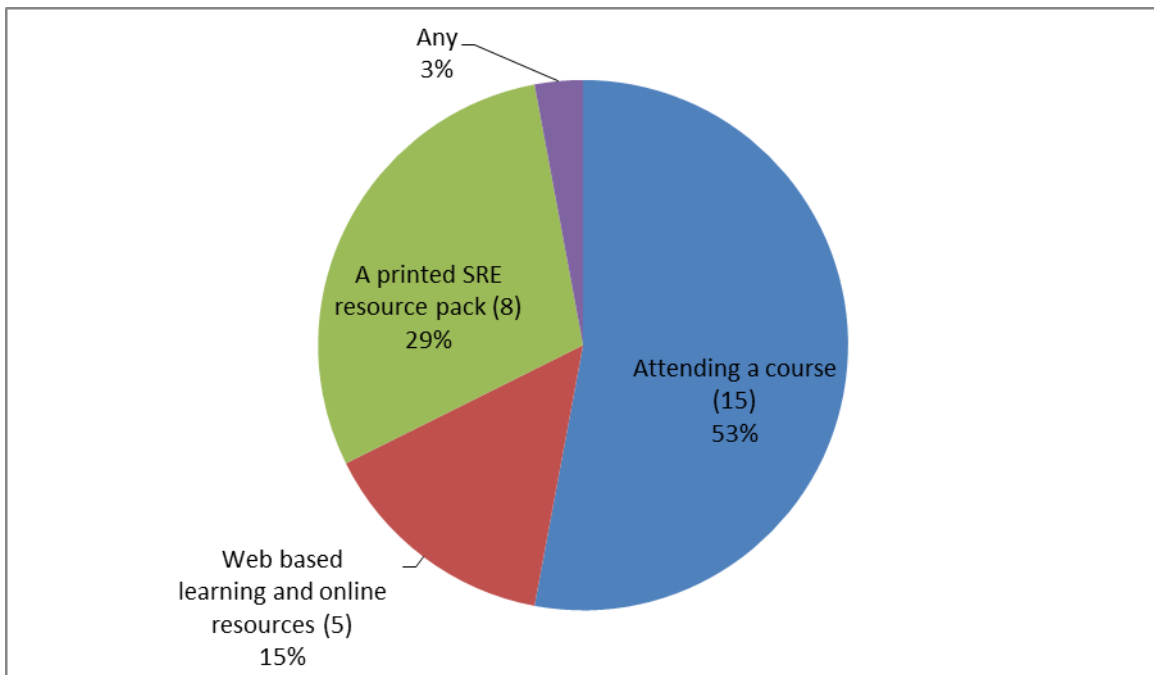
4. Have you attended SRE training?



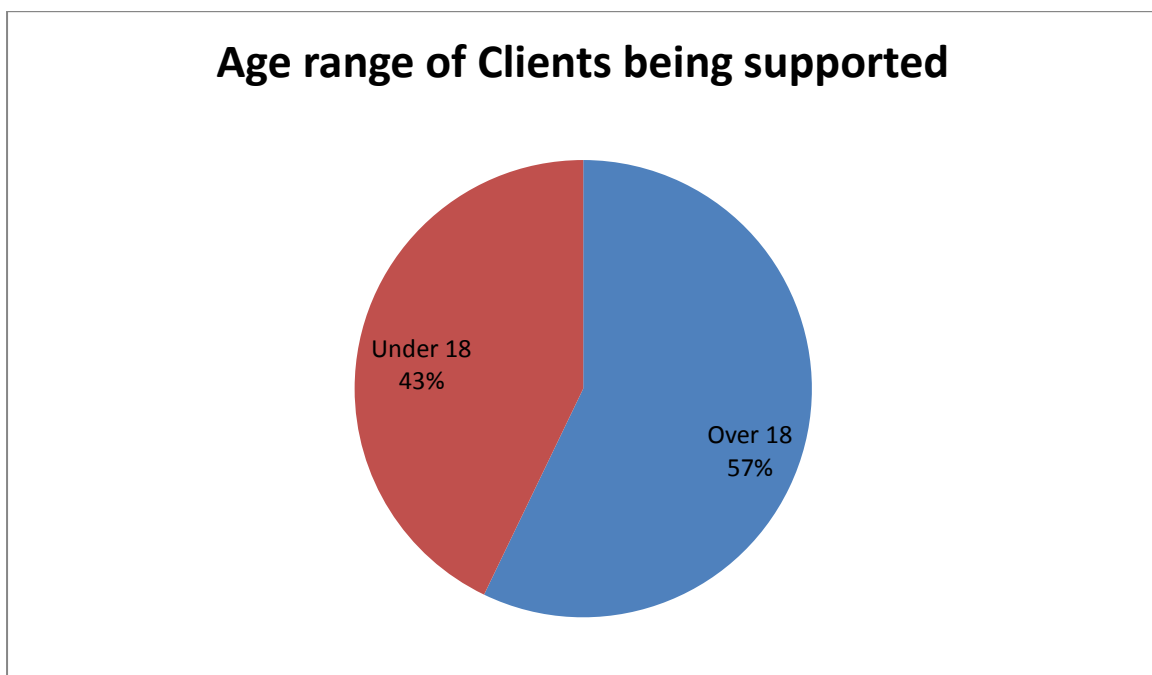
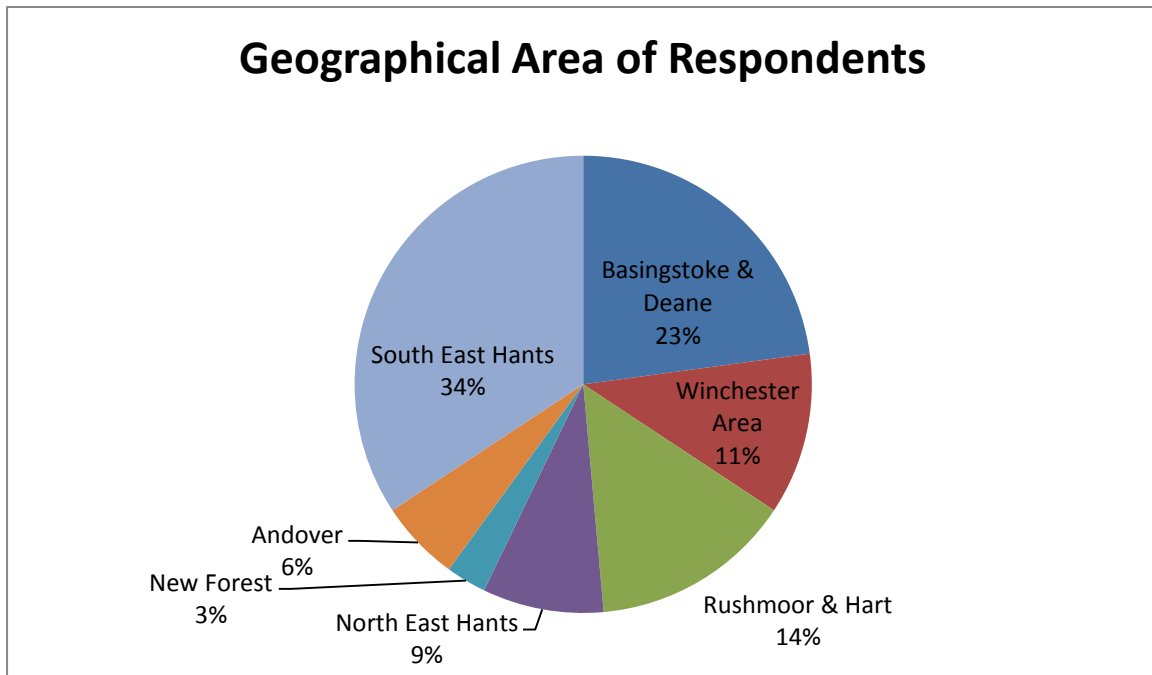
The majority of respondents had not attended any SRE training

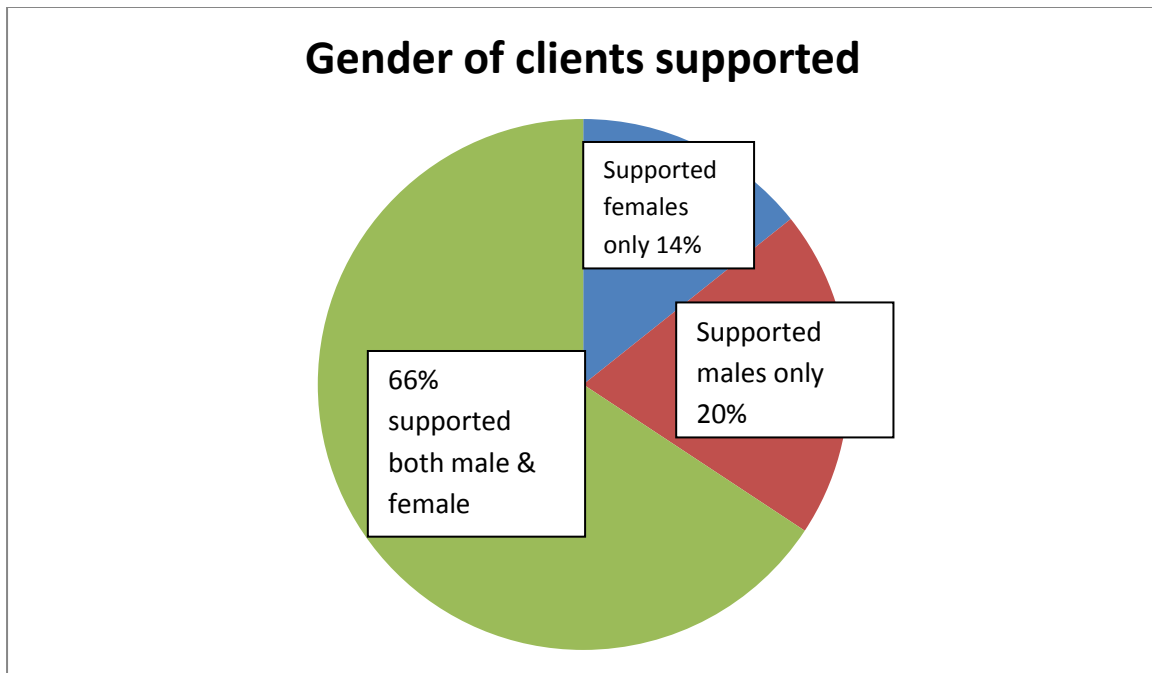
And

5. How would you prefer to receive SRE training?



The conclusion that we gained from this is there is a need for SRE training linked to local SH services using a range of methods, including online resources, SRE courses and a printed resource pack and we need to improve our signposting to Sexual Health Services, particularly within Hampshire.





Additional information

3 respondents asked for specialist clinics with longer appointment times and suggested that they could be either the first or the last appointment, 3 respondents asked for an Outreach or domiciliary service and 2 respondents asked for team training.

Other respondents asked for:

- Regular 'get-together' for young people living with LD with other young people living with LD either in single sex or mixed sex groups where they could discuss relationships and sex in a safe environment as there is such a range of abilities and the groups would then have to be tailored to each groups needs and could include Role Play, giving language that young people could use, similar to Peer Production sessions.
- 2 respondents asked for more appropriate training literature i.e. in more simple easy to read formats
- 2 respondents asked for specific SRE for people on the autistic spectrum, in particular on relationship differences i.e. friendship, appropriate touching, 'dating' and a sexual relationships

Conclusion

There appears to be a need for specialist LD SRE training in Hampshire for professionals, parents, carers and volunteers. The preferred mode of delivery is face to face, however with improved technology it could potentially be delivered in three ways; face to face, on-line and a resource pack.

There are some very limited resources available including books from FPA, specifically for young people on the autistic spectrums. Resources are expensive which may deter some from accessing them; however the book list would be a good resource for professionals depending on their budget. Other useful resources are:

Adult Learning in Hampshire, www.hants.gov.uk/hampshire-learning

Carers- www.hants.gov.uk/carers

Easy Health (for easy to read leaflets) www.easyhealth.org.uk/categories/health-leaflets

Parentvoice for <25yr olds- www.parentvoice.info

There is also recognition that LD covers a very wide range of abilities and challenges.

There is an identified need for specialist clinics within SHS in addition to the extension of the Community Team role. SHS are in the process of rolling out specialist clinics, known as SHIELD clinics in all its hubs.

There are opportunities for collaborative training and information sharing. Referring to The Hampshire Plan for Learning Disabilities, sexual health is mentioned but the sexual health provider isn't.

The Hampshire Plan provides a platform to move the findings of this work forward.

Appendix

- **HCC LD Development Plan**



LDPlanJan2016.pdf

- **Northern Ireland Needs assessment**



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ual-health-and-people

- **HCC Adults Health and Care Risk Assessment**



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- **Copy of Questionnaire**



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