

A Sexual Health Needs Assessment 2018

Supporting individuals with a Learning Disability living in Hampshire, Southampton and Portsmouth

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The Assessment Team

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Our values are:



Honesty



Everyone counts



Accountable



Respectful



Teamwork

For more information about the contents of this report please contact:

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This report was commissioned by Hampshire County Council, Sexual Health Commissioners as part of the contract with Solent NHS Trust to provide Sexual Health Promotion Services to local residents.

Introduction

Solent NHS Trust was commissioned by the Public Health Team at Hampshire County Council to undertake a sexual health Assessment of Adults Living with a Learning Disability.

As a service we strive to deliver equitable sexual health care to all our sexually active patients and this may include clinical interventions in either Clinical or Outreach settings, behaviour change interventions, education or empowerment through one to one 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 a 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'

This is Part 2 of 2 Parts. Part 2 focused on People Living With a Learning Disability (PLWLD), and this was undertaken between October 2017 and February 2018.

Our Needs Assessment Part 2 took the same format as with Part 1. We questioned 54 people living with a learning disability (PLWLD) across Hampshire. However, we decided that we would do this in group settings and 121s and we also realised that the Practitioner would have to go through all of the questions with the client group trying to avoid any bias by at least being aware this might occur due to the help some of PLWLD may require.

Background

We took advice from Learning Disability Teams with Solent and Southern Health, Mencap and HCC Disability Forums and Solent's Accessibility Team.

Having learned that there is a need for specialist LD Sex and Relationship Education (SRE) training in Hampshire for Professionals, parents, carers and volunteers we then made the assumption that there would be the same need for PLWLD as the groups they would get their information from were not well informed.

We know that there is a limited amount of this being delivered in parts of Hampshire through 'Ready to Shine' (www.ready2Shine.co.uk), but we also know that resources are limited and costly.

The other Challenge is that PLWLD cover a wide range of conditions and many conditions also have Physical Disabilities.

Also, it is evident that reading difficulties are observed among students with learning disabilities more than any other problem area of academic performance. While it is estimated at least 60% of students with LD having reading difficulties (Bender,2001) according to Hunt and Marshall (2005), some students lack the skills required for understanding text they read and have poor word analysis skills.

Methodology

The team developed a questionnaire in order to provide a better understanding of the needs of PWLD in relation to SRE to help to reduce the risk of sexual exploitation, unplanned pregnancy including babies taken into care and sexually transmitted infections.

Having had the experience of collecting questionnaires for Part 1 we realised that a slightly different approach was needed for this challenging group and we would be more successful if we worked with groups as well as 121s but all needed Face to Face contact. For this to be successful we would need to collaborate with Partners, Colleges, Mencap and other health care providers.

We then looked at our Questionnaire. So that our results could be matched with the Survey for Part 1 we wanted to use the same questions but understood that they would need to be in a slightly different format so that they could be understood by all and may require slight local alterations.

We contacted Solent Assess ability Team who looked at the written questions and put them in a more Assessable format.

(Questionnaires can be found in the Appendix)

We had three Practitioners delivering the questionnaires and they were split over 3 areas, South East, North East and West. They contacted the Providers of Day Services for PLWLD.

South East

The Practitioner contacted a non-statutory LD provider in the area with whom we had recently supported staff with educational material and provided a sexual health service update. This provider has 4 supported accommodation venues across the area. After contact was made with the provider, a copy of the questionnaire was sent to the management. This proved unsuccessful despite initial positive responses from the organisation.

However, on a more positive note we ran 3 other successful events gathering information.

Highbury College, we ran at a session and the group answered the questions using The Always Event PowerPoint developed by Solent Accessible Information (AI) Team reflecting the questions in this Needs Assessment. Individual forms were filled in prior to the visit with support of LD Lecturer on the Foundations Prospect Course.

Always Event, this event was supported by Solent AI team & Southern Health LD Staff, letters were distributed and two PLWLD attended Havant Plaza.

We choose venues based on previous good contact; however most weren't forthcoming which was disappointing as previously mentioned. Highbury College was very positive and proactive.

This continues as students are requesting to visit Sexual Health Service at St Mary's Campus as part of their course and gave feedback on the Sexual Health Service/ accessibility.

The North East

The Practitioner met with Mencap staff who advised it would be beneficial to attend The May Club in Basingstoke which has an average of 65-75 adults who attend regularly to socialise in a fun way comprising of Disco, Board games and Bingo.

The relevance of the Survey was discussed, expressing the need to protect the rights of the Service Users and their rights to a relationship and to express their sexuality.

It was arranged that we would be visible to Service Users and that we would be separate and in a quieter area for confidentiality in order to engage conversation so to complete the questionnaire.

We picked this venue because in Basingstoke Mencap are an Independent registered Charity providing support and services for Children/ Young People and Adults with LD and /or Mental health issues along with their families and carers in the local area.

We completed 23 questionnaires, the majority of these were 121 and some with the support of their key worker (we were aware that this would incur some bias) However, we were also aware that some PLWLD may need support to understand the information, when communicating it's important to always use accessible language, avoiding jargon and long words that may be hard to understand, also thinking of tone of voice and body language as well as words used and listening. Asking each question and giving time for a response. Some service users are able to read, understand and answer the questions themselves but others aren't.

The level of support someone needs depends on the individual so adapting the way we were asking the questions helped by explaining the context in more detail, for example Relationships? What is Sex? Once we could establish that the service user had understood the question whether that was with the support of the keyworker/ friend or they felt that they were able to answer.

An example of the approach taken to gain the survey completion by some service users so that they were able to understand what is being asked of them was to use a couple of social stories about personal space and hugs, asking if this was "Ok" or "not Ok?" And if they "didn't want or like" what the picture in the story showed they could then tell the other person, clearly and positively. The service users really liked that approach and engaged really well.

We contacted Parkside, they are a registered charity based in Aldershot that provides support services for children and adults with learning disabilities, unfortunately after a few attempts to arrange a visit they declined.

We contacted Alton College as they offer a wide range of additional support for learning; from regular one-to-one help for a wide variety of Specific Learning Need.

3 students live in Aldershot & the other 8 across East Hants.

The students attended in small groups of 2 & 3 based on their specific need and the level of support required. One of the groups had support staffs that were able to communicate for us.

2 of the young people said *“it would be embarrassing to talk to members of their family and even to talk to some teachers so having someone come in like us would be great”*.

The West

We contacted Mencap Southampton and Learning Disability Winchester Gold, this is a local charity in Winchester that offers a range of weekly and monthly activities as well as providing information, signposting and skills workshops.

We picked this venue because they provide the services for PLWLD and are central to PLWLD access.

The Practitioners all worked with the same values and ethos within the code of conduct for Solent NHS Trust and in the West as NE were found to be fully supportive and provided a protected place to work. Again some of the Service users required support and a few didn't, and one service user used Makaton and as the Practitioner also could use Makaton this was very successful and he were able to complete the questionnaire.

We wanted to compare our results with the results in Part 1 and wanted to understand if Practitioners found this survey more challenging than our previous survey and if they did and why.

One practitioner reported that working with Service Users easier than working with Parents, Carers, this was because contacts had already been made in a previous role, where another Practitioner faced greater barriers with the added challenge of having to tailor all questionnaires to meet the needs of the client group. This barrier was around known contacts being reluctant to engage where they were happy to engage with the previous survey, which made us wonder in this ever changing financial and contracting environment they feared if they engaged and didn't receive positive results that they would face criticism which may be held against them, or were they simply far too busy and RSE just wasn't a priority. The 3rd Practitioner wasn't involved in Part 1.

Practitioners reported that they had to do a lot of adapting their delivery style of the survey, so we wanted to understand why this was necessary.

The Practitioners found that they had to adapt the questionnaires so that they could ensure that as they were talking and that they were engaging at an appropriate level so that they were able to meet the needs of each Service User. This meant that the questionnaire had to be tailored to the specific need of each service user without compromising the answers therefore trying to avoid any bias.

Survey Aims and Objectives

The aim of the survey was to establish the confidence and competence of PLWLD to discuss Sex and Relationships and to know how to access Sexual Health Clinics if required.

The main theme that the questionnaire covered was around the respondent's knowledge of SRE.

The main gaps in our knowledge were identified.

To establish our audience:

- Where did they live?
- How old where they?
- Living circumstances?
- Gender?

To establish if SRE training was needed and how it should be delivered:

- Are they able to discuss Relationships with those that support them?
- Are you able to talk about your body, Sex and Sexual Health with the people that support them?
- Are they able to say no if they didn't want to be touched or to have sex?
- Where do they get their information from around this subject?
- Have they received any SRE?
- How would they like to receive that information?

Scope

54 individuals completed the questionnaire across Hampshire.

One group of 15 students from a Portsmouth college with a county wide catchment discussed the questionnaire - see qualitative research.

Analysis

Qualitative Data

Question 6 asked participants "Is there anything else you would like to say?"

From Basingstoke:

- Where is my local clinic?
- What happens in clinic?

- Can we get a clinic set up here?
- I am over 18yrs old am I allowed to have sex in a relationship?
- How do I know if I am using a condom correctly? Who can show me? Where are the leaflets to explain, easy to read and with pictures?
- What happens if I get pregnant?
- Would like more support with relationships, love and sex?

From Winchester:

- 'More help about relationships. Someone to come out and do a talk about sex'
- 'Someone to come and talk to us. Where is the clinic?'
- 'To know what is right and not right. All people should be treated the same, doesn't matter what they are like, should still be able to have help'
- 'Don't know where my local clinic is'

From Eastleigh:

- Where are the clinics? Help with how to have a date. Confused about how I get pregnant and how to get a test?

From Southampton:

- 'Internet can have nastiness/frauds/porn...and hurt younger ages. I also might like to read/learn more about sex/relationships'

From Test Valley:

- 'Would like a relationship but not had a positive experience and it put me off. Like to know how to have a relationship'

From Gosport and Fareham

- 'Would like different tips on condoms and contraception'
- Access to information, leaflets I can understand-no writing'

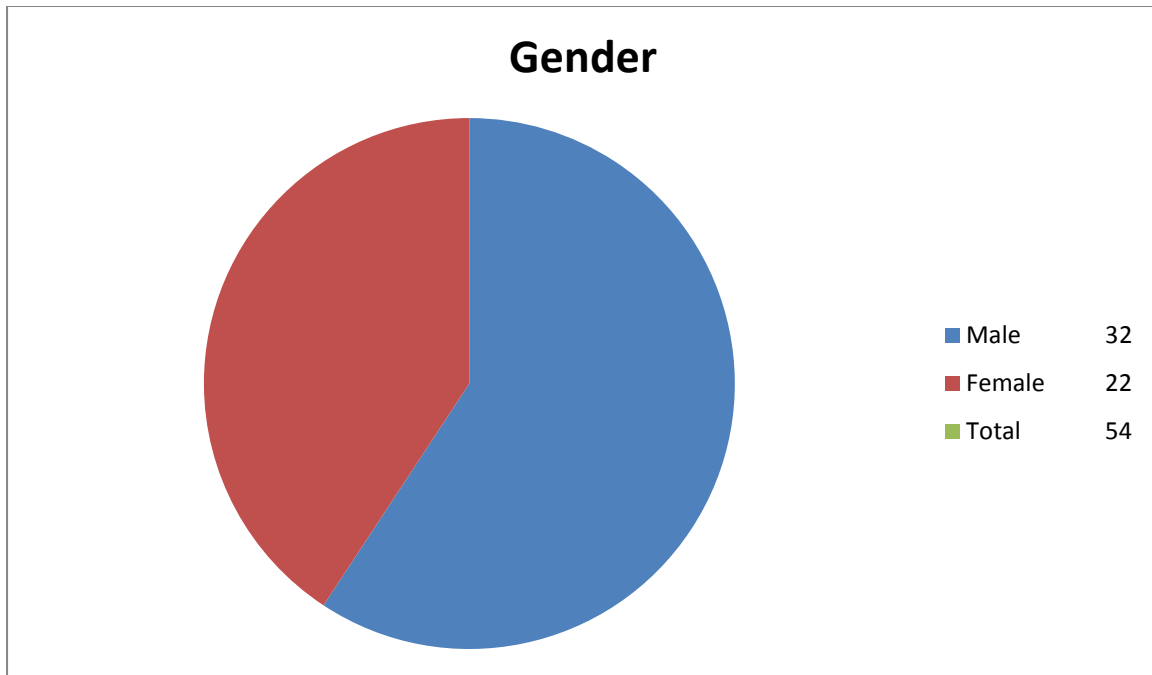
The findings from a group discussion at Highbury College:

- 'I talk to friends, college mentor, talk to family, talk to tutors at college. I find it easier to talk about relationships and much harder to talk about sex'
- 'I have talked to a college Nurse'
- 'I have spoken to a doctor'
- 'Would like more education at school'
- 'Would like help identifying safe websites'
- 'Would like a tour of the sexual health department'
- 'Think that you should learn more about sex when you are younger'
- 'Talk to parents about sex'
- 'Learn about Sex in School'
- 'You should be older when educated about sex and relationships'

- 'Learn about sex education in school'
- 'Haven't learnt about sex and relationships in college'

Quantitative Data

Gender



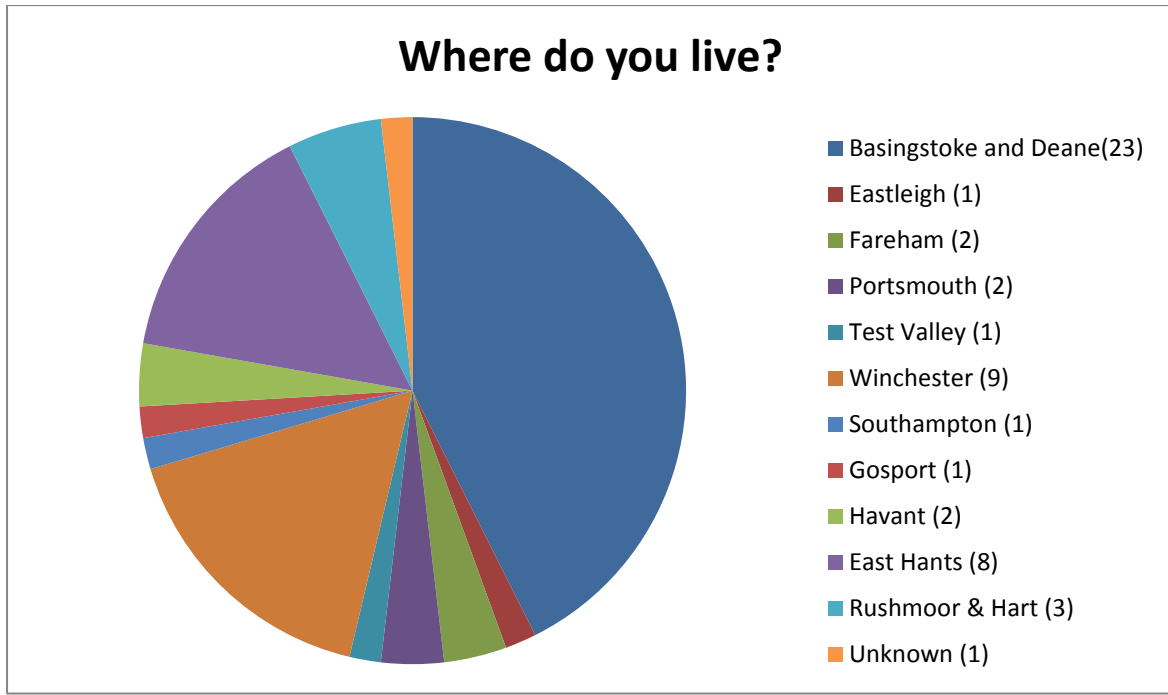
There were 32 males and 22 female participants in this assessment from across Hampshire.

This broken down into areas as below:

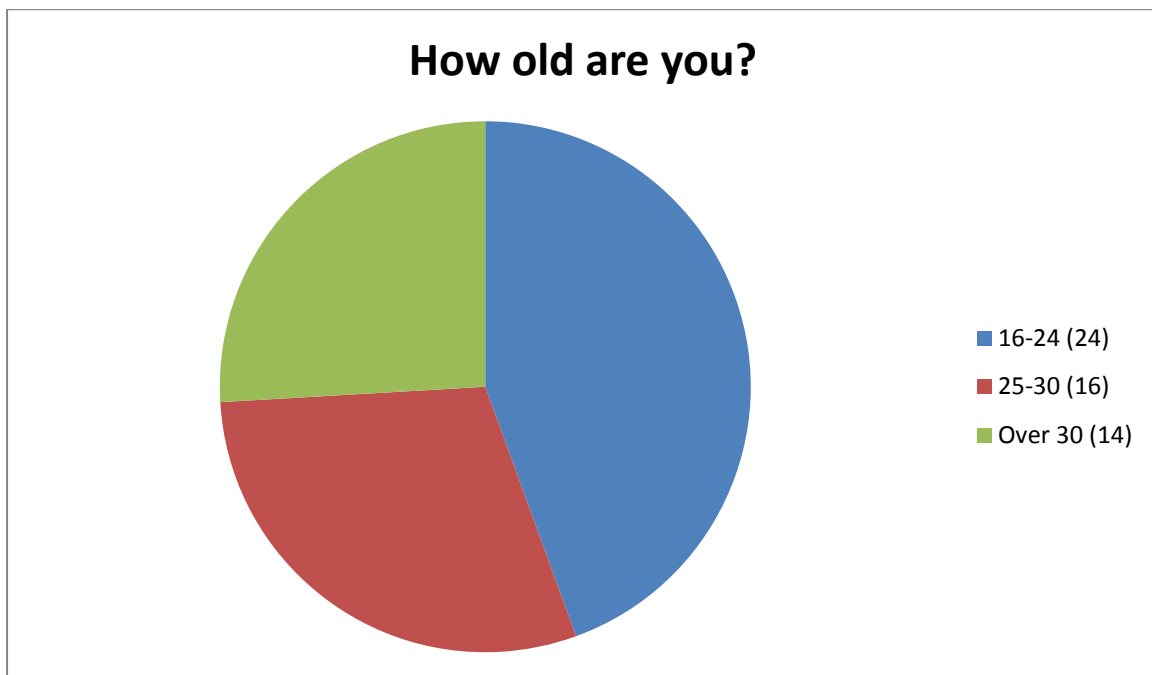
Area	Male	Female
Basingstoke	14	9
South East	7	8
West	3	2
North East	8	3

One group of 15 students from a Portsmouth college with a county wide catchment discussed the questionnaire- see qualitative research.

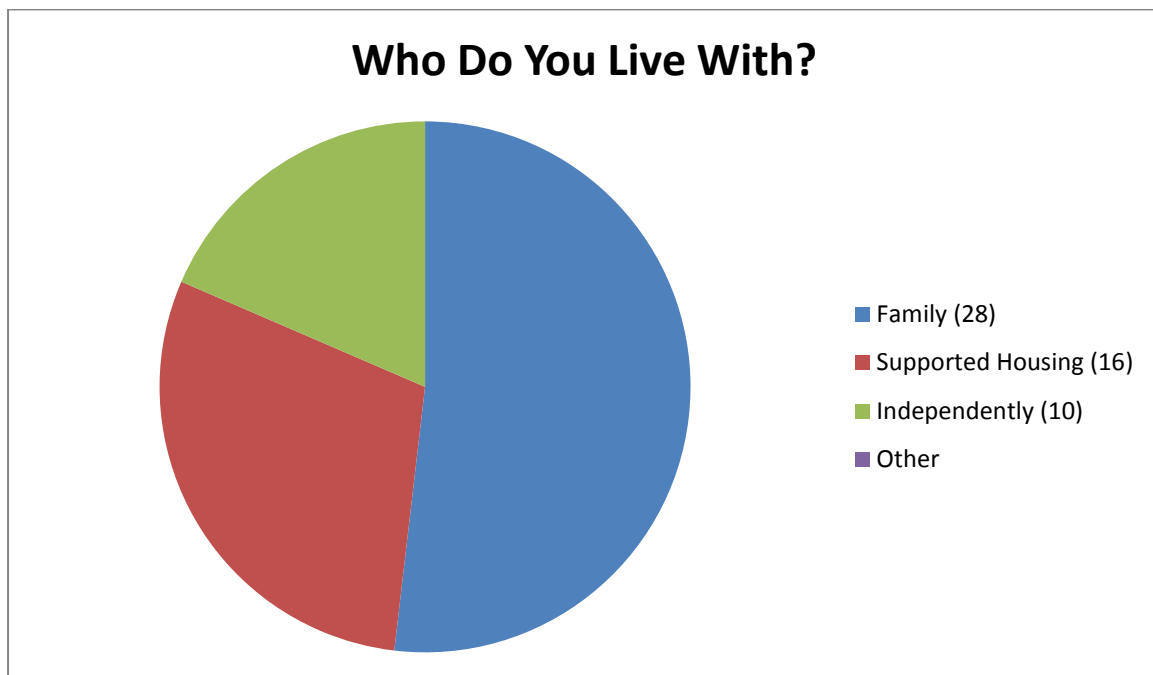
Question 1: Where do you live in Hampshire?



Question 2: How old are you?



Question 3: Who do you live with?

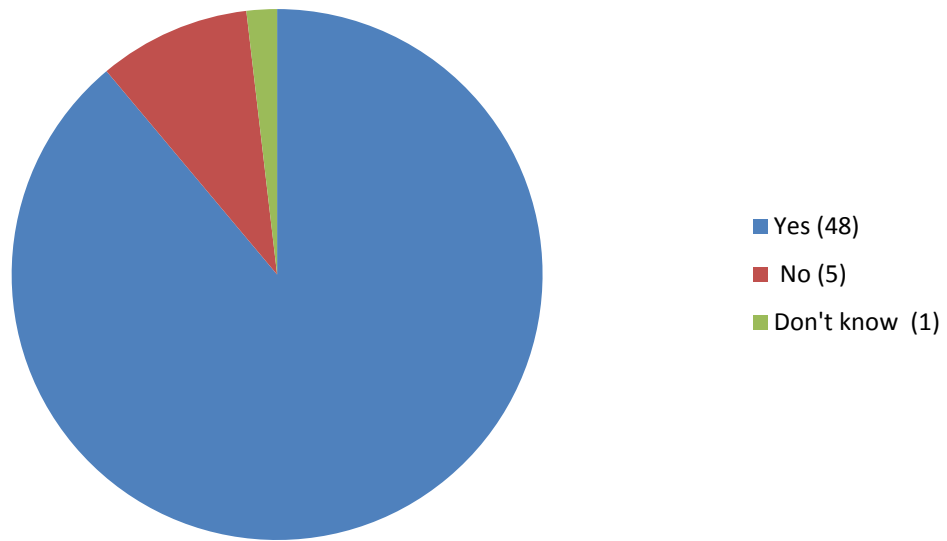


Questions related to Relationship and Sex Education

Question 1: Are you able to talk to the people who support you about ...

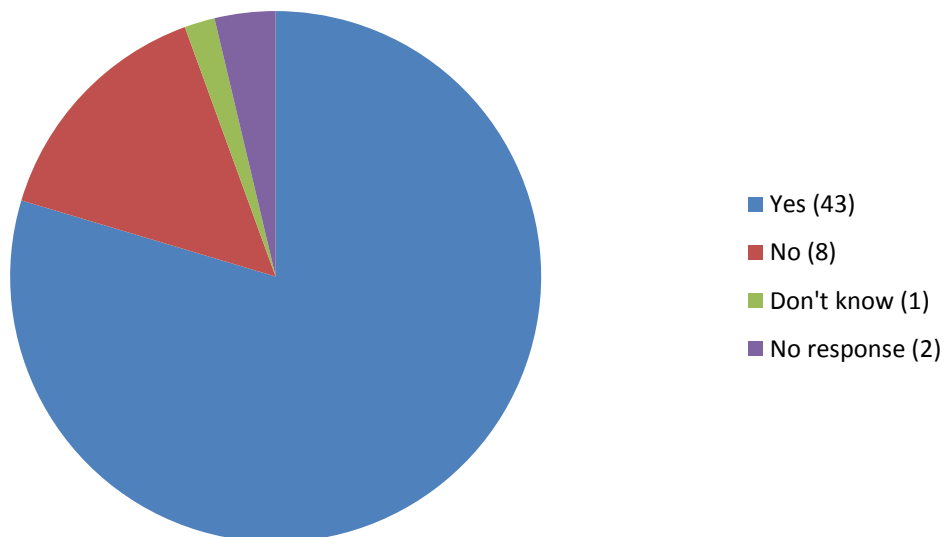
a) Relationships, boyfriends and girlfriends?

Relationships- Boyfriends or Girlfriends?



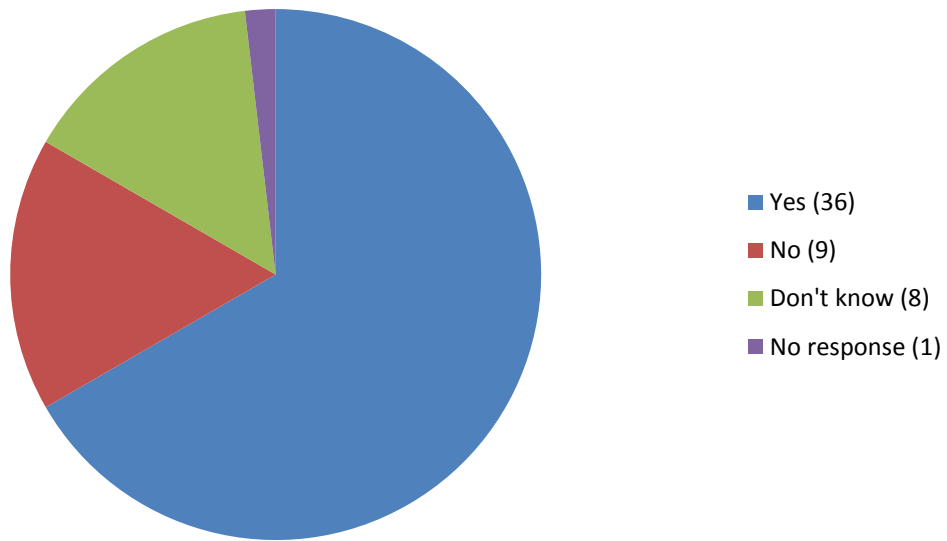
b) Question : Are you able to talk to people who support you about Your Body, Sex and Sexual Health?

Your Body, Sex and Sexual health?



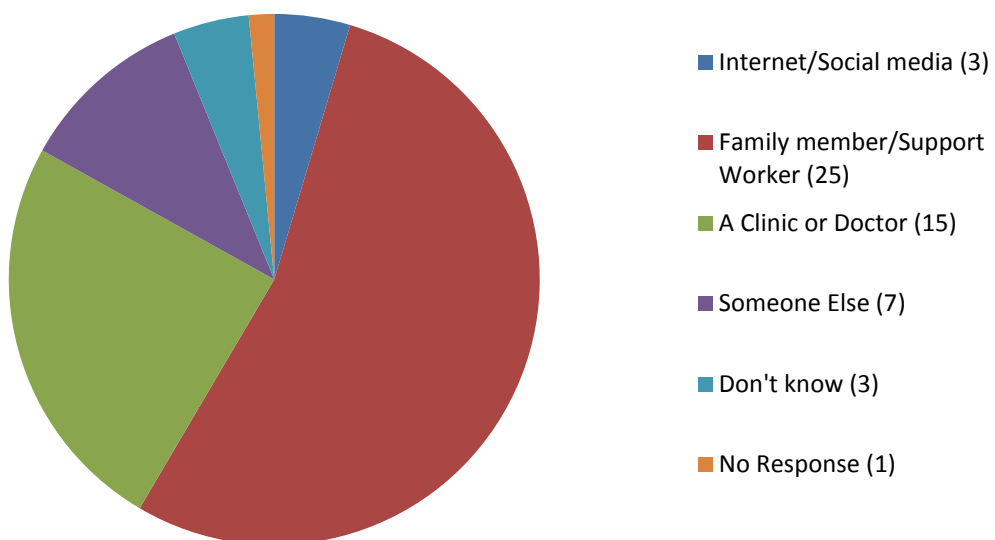
Question 2: If someone wanted to have sex with you or touch you, would you be able to say "no" if you didn't want them to do that?

Do You Feel Able To Say No?



Question 3: Where would you go for help and information about relationships and sex?

Sources of help and Information

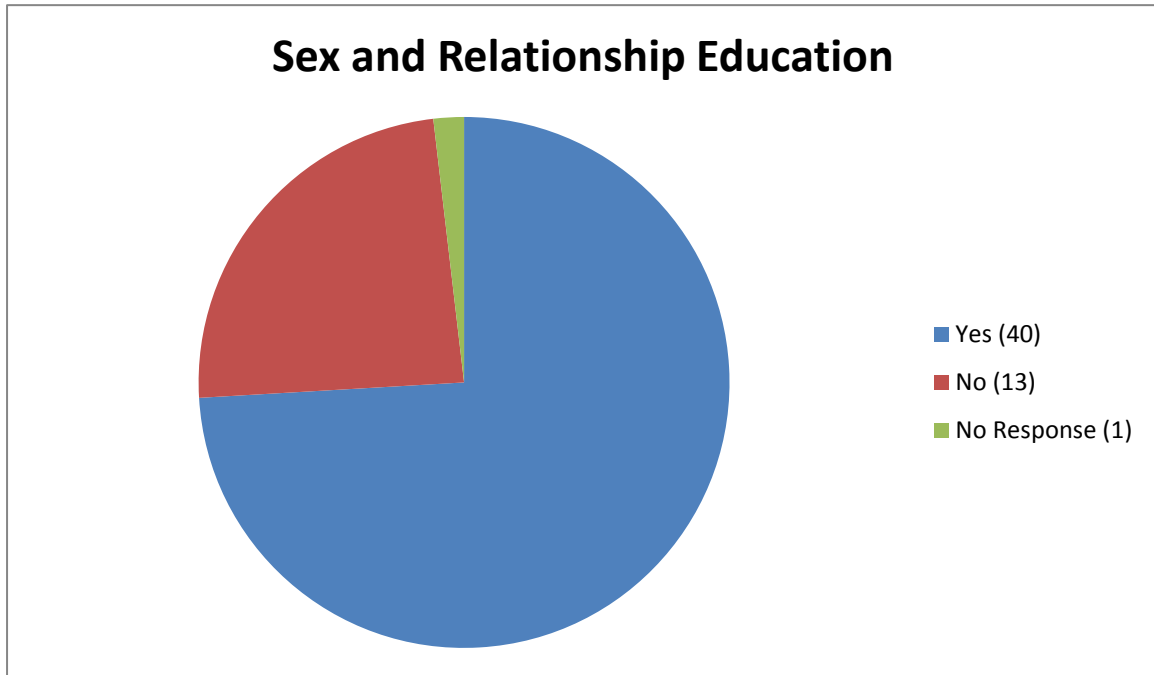


Responses when answered 'Someone else':

- "Teacher"
- "Mencap Group"

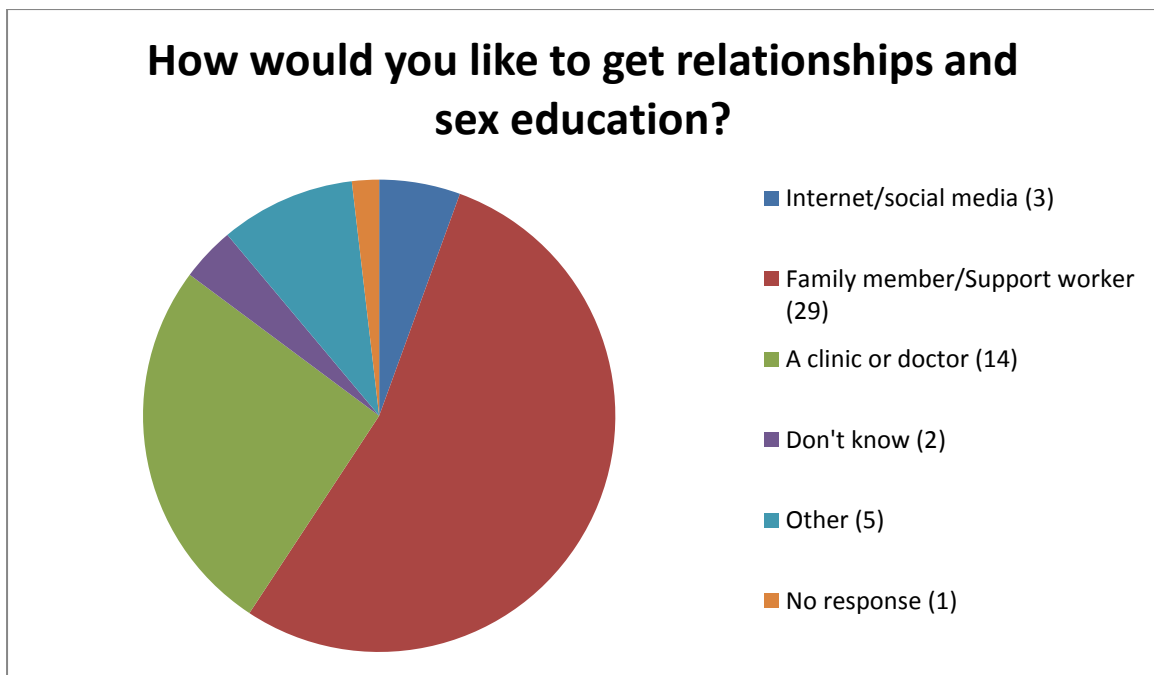
- “Winchester Gold”
- “College”

Question 4: Have you had any education about relationships and sex?



Responses: “This isn’t delivered in a formal way”

Question 5: How would you like to get relationships and sex education?



Responses when answered other:

- “Mencap”
- “Winchester Gold”
- “Books”

Overarching Themes with the results

- Ages of respondents provided a wide age group
- They mostly lived at home with family
- They were able to talk about relationships with someone who supports them and also talk about their bodies, sex and sexual health
- The respondents were able to say ‘No’ to unwanted sexual advances
- They mostly got their information from a family member/ Support worker but a large number didn’t and got this information from a Doctor or clinic
- They mostly had received RSE
- They would mostly like to get their information from Family member/Support worker but a large proportion wanted this from a Doctor or clinic.

There also seems to be two sets of themes going on, The Qualitative and the Quantitative information seem to be at odds with one another and wonder if this reflects Bias here as most of the respondents would have had someone to help them fill in the form but in a group they felt free to speak for themselves and were able to ask what they wanted. Therefore the Qualitative information was a better reflection of their knowledge and needs.

Comparing this to the information from Part 1:

- Where the majority of respondents did not feel confident and /or competent to discuss relationships and sex with the people that they are caring for PLWLD did feel confident and competent to discuss and ask for advice
- The majority of respondents did not feel able to identify risky behaviours
- The majority of respondents did not know how to access Sexual health Services
- The majority of respondents haven’t attended any SRE/RSE training.

Additional Information:

As a result of the work the team have been doing with regards to the Needs Assessment we were invited to attend an ‘Always Event’ in Havant that Solent Access ability Team organised.

The background to this Event.

The NHS 5 year Forward View 2014 sets out a shared vision for the future of the NHS. It addresses widening gaps in the health of the population, quality of care and funding of services and describes the future shaped both by new models of care and by new relationships with patients and communities. Building on the Institute for Healthcare Improvements in the US, the development of

Always Events within NHS care systems and organisations will strengthen the voice of those using health services, their Carers, families and staff enabling a pro-active approach.

Building the right support: A national plan to develop a community services and close in patient facilities for PLWLD including Autism (2015).

Leading change, adding value (2016), A Framework for Nursing, Midwifery & Care Staff highlights 'The Triple Aim' of measuring to enhance better outcomes, better experiences and better resources across care, which are the main objective of Always Events.

As Always Events are defined as 'those aspects of the patient and family experience that should always occur when patients interact with healthcare professionals & the delivery system- we should work within a Framework, commitment 5 states, 'we will work in Partnership with individuals, their families, Carers and others important to them'.

This Programme ran from 2015 until April 2016 and engaged in a 10 provider pilot sites across England within NHS in England and in 2016 and 2017 which was the 3rd phase

Conclusion and Recommendations

The first thing to mention is that there have been noticeable improvements in professional awareness of this issue since we started gathering information for these surveys in 2016-17, including Hampshire County Council Learning Disability Partnership Board, Solent Accessibility Information Team who created the Always Event with the support of Southern Health NHS Trust LD team.

However, there is a long way to go before we can say that most PLWLD are able to engage in safe, happy, healthy sexual and personal relationship.

There were some surprises in our results:

- That 1/3 of respondents wanted to receive help and information about SRE from clinical staff
- 3/4 had had SRE which was positive but sadly the learning outcomes appeared not to have been met
- It was positive that the respondents had very good support and good relationships with their support people so that they could talk about SRE, their bodies, sex and sexual health but their support people didn't feel that they had the relevant information or the confidences to deliver this.

The greatest challenge would appear to be to up skill the Carers, Professional and the Parents so that PLWLD aren't so reliant on clinical staff for the information that they can trust.

There needs to be easy to find and readily available easy to read leaflets and electronic information for all service users.

Moving forward we should focus on forging local relationships with LD Groups.

We would like to provide training about Values, Attitudes, Safety and rights in relation to Sexuality and Relationships for PLWLD and those that support them.

We should have an LD link to www.letstalkaboutit.nhs.uk.

We would like to recommend:

- A Needs Assessment for 13-18yr olds asking similar questions and then comparing the answers.
- More training for clinical staff on the needs of PLWLD so that clinical staff has an improved awareness and appropriate appointments can be made for this patient group.
- A Training booklet that Professionals, Carers and Families could work through.
- Training packages that Professionals, Carers and Families; this may include a booklet but could also be an On-Line Course.

References

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<https://www.england.nhs.uk/ourwork/leading-change/>

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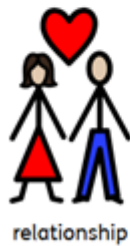
Appendix



Vision statement:

'I will always feel confident to talk about relationships and sex'

When we talk about 'sexual health' there are two parts;



relationship



Your body



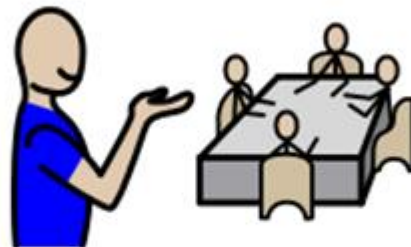
What is your experience of getting help with relationships and sex?



How did you learn about relationships and sex?



What should services do differently to help you with relationships and sex?



Thank you!
What will happen next...



Contact details:

You could see us at:



Aldershot Centre for Health
Telephone: 02380 540400



Crown Heights, Basingstoke
Telephone: 02380 540400



Royal South Hants Hospital in
Southampton
Telephone: 02380 540181



St Mary's Hospital in Portsmouth
Telephone: 02380 540454



If you have any problems
contacting us, our Patient Advisory
Liaison Service (PALS) can help
Telephone 0800 013 2319

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SHIELD Clinic



Sexual Health Clinics for People with a Learning Disability



You might want to look at this leaflet
with your someone who supports you.



Easy Read Leaflet

What is a SHIELD Clinic?

	SHIELD is a friendly sexual health clinic for people with a learning disability.
	To see you will need someone to make a referral with you, or you can refer yourself.
	We will tell you or your supporter about your appointment by phone or letter.
	When you arrive at the clinic you will be seen quickly. You won't have to wait long.

	You will have time with a nurse to talk about your sexual health and preventing infections. You can find out if you need any tests.
	You can talk about contraception which can stop you having a baby. You can decide which is best for you.
	Everything will be free.
	The team will help you to learn about relationships and how to keep safe in a relationship.
	Everything you say will be confidential. Your information will only be shared if we are worried about your safety. We will talk to you about this.

Questionnaires

Sexual health needs survey 2018

Solent Sexual Health Services are asking adults who have a learning disability to answer a few questions. Your answers will help us improve the services we provide you.

1. Where do you live in Hampshire?

- Rushmoor and Hart
- Basingstoke and Deane
- Eastleigh
- New Forest
- Fareham
- Portsmouth
- East Hants
- Test Valley
- Winchester
- Southampton
- Gosport
- Havant

2. What is your postcode?

3. How old are you?

- 16 to 24
- 25 to 30
- 30 or older

4. Who do you live with?

- Family
- Independently
- Supported housing
- Other (please give details below)

5. Are you able to talk to the people who support you about?

a. Relationships – boyfriends or girlfriends?

- Yes
- No

b. Your body, sex and sexual health?

- Yes
- No

6. If someone wanted to have sex with you or touch you, but you didn't want them to, would you feel able to say no?

- Yes
- No

7. Where would you go for help and information about relationships and sex?

- The internet/social media
- Family, friends or a support worker
- GP or clinic
- Don't know
- Other (please give details below)

8. Has anyone talked to you about relationships and sex?

- Yes
- No

If yes, who talked to you?

9. How would you like to find out about relationships and sex?

- From the internet/social media
- Family, friend or support worker
- GP or clinic
- Don't know
- Other (please give details below)