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D/deaf People's Access to Sexual Health Support & Information

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BA SOCIOLOGY & SOCIAL POLICY W/ A YEAR IN CHINA

Contents

Acknowledgements	3
List of abbreviations	4
Executive Summary	5
Aims	5
Methodology.....	5
Findings	5
Recommendations for best practice.....	5
Interchange	6
Sahir House	6
Merseyside Society for Deaf People	7
Research context	8
Policy Context	9
Research Aims	10
Methodology	10
Data Collection	10
Ethical Considerations.....	10
Reasoning and Rationale.....	11
Data analysis methods	12
Findings	13
1. Generational differences in D/deaf education and welfare	13
2. Barriers in accessing sexual health information	14
3. Lack of D/deaf awareness	16
4. Interpretation.....	17
5. Fitting into services	19
Discussion	20
Recommendations for best practice in the area	21
D/deaf awareness	21
Further research into interpreter training and interpreter guidelines.....	21
Research into interpreting options	21
Advertise as D/deaf friendly & D/deaf outreach	22

More robust links with the D/deaf community and sexual health services	22
Conclusion	23
Bibliography	24
Appendix	27
Deaf or deaf?	27
Services that provide direct HIV and sexual health information and services to D/deaf people	28
Data collection details	29
Table 1 - Sahir House Staff focus group	29
Table 2 - MSDP staff focus group.....	29
Table 3 - Sahir House volunteers focus group	29
Table 4 - Qualitative survey	29
Participant Information Sheets and Consent forms	30

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Finally, my deepest gratitude goes to the staff at Merseyside Society for Deaf People without whom this research wouldn't be possible.

List of abbreviations

BDA	-	British Deaf Association
BSL	-	British Sign Language
D/deaf	-	[See appendix]
EARS	-	Education & Advice on Relationships and Sex
HIV	-	Human Immunodeficiency Virus
LGBT	-	Lesbian, Gay, Bisexual and Transgender
MSDP	-	Merseyside Society for Deaf People
NHS	-	National Health Service
SRE	-	Sex & Relationship Education
UK	-	United Kingdom

Executive Summary

Sahir House in their ongoing work providing HIV support in Merseyside have recognised that there is a lack of sexual health support for D/deaf people and a disproportionate need. The impetus for this research comes from their collaborative work with Merseyside Society for Deaf People.

Aims

This report is aimed at understanding what barriers MSDP and Sahir House have experienced in providing sexual health support to their D/deaf service-users, what sexual health resources are currently available for D/deaf people and what is best practice for working with interpreters in this field. Current research indicates that D/deaf people have a lower understanding of sexual health and suffer from worse health outcomes because of the failure of health services.

Methodology

Data gathered from 3 focus groups and a qualitative survey has been coded and analysed using a thematic analysis. The focus groups were of Sahir House staff, MSDP staff and Sahir House volunteers. The qualitative survey participant was a healthcare professional.

Findings

1. Generational differences in D/deaf education and welfare
2. Barriers in accessing sexual health information
3. Lack of D/deaf awareness
4. Interpretation
5. Fitting into pre-existing services

D/deaf people experience many barriers in accessing sexual health support. This research argues D/deaf people's needs are not being met in several ways. Many older generations of D/deaf people aren't sexual health aware because of exclusion from public health campaigns and having no adequate sexual health education in school. Sexual health resources exclude D/deaf people with low English literacy because they require visual communication and cannot equally access resources. A significant barrier is the lack of awareness of D/deaf people's needs such as visual information and the importance of booking an interpreter. The quality of an interpreting service has a large impact on how much the D/deaf service-user will benefit and using interpreters in sexual health settings present unique challenges regarding confidentiality especially within the D/deaf community.

Recommendations for best practice

- Deaf awareness training;
- Further research into interpreter training and guidelines;
- Research into interpreting services available;
- Advertise as D/deaf friendly & D/deaf outreach;
- More robust links with the D/deaf community and sexual health services.



Interchange

Interchange is a registered charity (charity number:1038129) which aims to connect non-profit, voluntary and community organisations who have research or work-based learning project needs with students in Higher Education who are looking for these opportunities. Through collaborative effort, these organisations gain the expertise and input of higher education students who are able to conduct research projects on their behalf while the students are able to gain valuable experience in the field of social research with specialist support and access to specific samples. It is through Interchange that many projects such as this one is assigned to Sociology, Social Policy and Criminology students.

The Department of Sociology, Sociology and Social Policy utilises a 'critical pedagogy' meaning it is invested in being a part of a higher education which offers a way of thinking outside of taken-for-granted ideas and promoting democratic knowledge production. Interchange allows for students and 3rd sector organisations to generate knowledge themselves without the usual economic strain and at the same time offering students the opportunity of doing first hand research. Organisations in the 3rd sector can use this research to improve and adapt their own services as well as for funding bids.

This report documents a collaborative project between Sahir House and myself, a final year undergraduate researcher from the University of Liverpool. I was supervised by Serena Cavanagh, Health Promotion Lead at Sahir House and by Dr Kay Inckle, lecturer at the University of Liverpool as well as receiving guidance from the Interchange office.



Sahir House

Founded in 1985, Sahir House (charity number: 1077327) has been offering HIV support, prevention, information and training across Merseyside for over 30 years. They work to increase HIV knowledge, reduce HIV stigma and campaign for HIV positive people's rights. They promote good health and provide care, support and practical assistance to people living with HIV and people affected by HIV. They also work to advance public education and reduce stigma regarding HIV. The services they provide include:

- Support services of coaching, advice, guidance, welfare rights, counselling and psychotherapy for people living with or affected by HIV
- HIV prevention, outreach and testing
- HIV awareness and stigma reduction training
- HIV health promotion, resources and information
- Asylum support and wellbeing

Their core values are as follows: **Empowering** its service-users to help themselves and achieve the goals they have set themselves. Providing a space of **safety** in which people can speak freely without fear of stigma and prejudice. They **welcome diversity**, recognising that all people have equal rights and value and such difference should be celebrated. **Ethical** partnership rather than competition should be sought out with integrity and mindfulness of the organisation's wider impact. Sahir House also recognises the **evolving** nature of its service-users and are committed to responding to the changing needs of its current and potential service-users.

The organisation is funded by local authorities and charitable trusts and works in close partnerships with several other Merseyside organisations.



Merseyside Society for Deaf People

Established in 1864, MSDP was founded to address the number of barriers and inequalities experienced by D/deaf people and seeks to help D/deaf people to achieve a full, active and influencing role in mainstream society. The organisation acts as a registered charity and limited company. Its services include support work, social work, technical equipment provision, interpretation, training and BSL courses. Sahir House has worked in collaboration with MSDP to deliver HIV awareness training and agreed to take part in the research process.

Research context

There are no reliable estimates on the number of D/deaf people and BSL users in the UK. According to official census statistics there are 56,400 registered D/deaf people in the UK with a further 156,500 that are hard of hearing. The BDA however, estimate it to be around 151,000 BSL users with 87,000 of which being D/deaf (2014). They also estimate a total of 9 million people in the UK are D/deaf or have some degree of hearing loss. D/deafness is the 3rd most common disability in the world and ranges from profound deafness to mild hearing loss. Many D/deaf people use sign language as their main form of communication. BSL is a fully functional language which uses visual hand gestures, body language, facial expressions and mouthing to communicate. It is an indigenous language to the UK but is a distinctly different language than spoken English with its own grammar and syntax. It also has regional dialects meaning two signers from opposite ends of the country won't necessarily be able to fully understand each other. The earliest documented use of sign language in the UK being used in 1576 (UCL Deafness Cognition and Language Research Centre, 2018). In 2003 BSL became officially recognised as a language in its own right however, doesn't hold the same protected language status that minority languages such as Welsh and Gaelic do (BDA, 2014).

Despite progressive policies and legislation there still remain inequalities between the D/deaf and hearing populations. Within health, "there is a likelihood of reduced life expectancy in Deaf people" according to research conducted by SignHealth (2014). Deaf people have particular difficulties in accessing health services due to unnecessary barriers in communicating with healthcare professionals due to a lack of high-quality interpreters and a lack of resources in BSL. While 8/10 D/deaf people in their research would prefer to use BSL to communicate with their doctor, only 3/10 get the chance, leading to poor diagnoses and treatments. Furthermore, of 533 Deaf surveyed during 2010-11, 46% currently communicated with health professionals by writing things down and 23% by lip reading and spoken English despite the fact that none preferred to communicate in these ways (Sign Health, 2013). Difficulties in making appointments, being forced to lip read and inconsiderate staff are all cited as reasons why D/deaf people are unhappy with the health services they have received.

This inequality is also found when accessing sexual health services as well as sexual health knowledge. The charity Deaf@x (2012) conducted their EARS research campaign on how accessible sexual health education is for D/deaf people. Their main findings were that of the D/deaf people surveyed:

- 35% did not receive any sex education at school
- 65% said that the information was inaccessible; the main reasons was that the information provided was limited (43%) and they could not understand the teachers (43%)
- 46% learnt about sex through the media
- 36% learnt through direct sexual experience

They also collected individual case studies which illustrate how these difficulties are experienced. As one D/deaf teenage mother illustrates:

“I didn’t know anything about sex, contraception or relationships when I left school, there was never anyone to ask who could explain properly to me in sign language” (EARS report, 2012)

Research conducted between Deaf@x and the British Pregnancy Association (2014) concluded that sexual and reproductive healthcare services and sex and relationship education are failing young D/deaf people. They argue that sex and relationship education is not being delivered to young D/deaf people at the same level as their hearing peers therefore, not adequately equipping D/deaf pupils to have healthy sexual and romantic relationships. Most schools in the UK are obliged to teach SRE however there remain disparities in the quality of education given with some only meeting the minimum standard by covering anatomy and not being proactive in covering LGBT sexualities and gender identity (Corteen, 2006). Young D/deaf people are also unable to access sexual and reproductive healthcare services when they need to with many not being provided communication support or accessible information during healthcare appointments (Deaf@x & BPAS, 2014). This is especially problematic considering how the D/deaf community have higher experiences of unplanned pregnancy and STIs when compared to the hearing population (SignHealth, 2014).

Policy Context

The inequalities outlined above exist despite legislation which legally obliges public services to support all citizens equally across a number of ‘protected characteristics’ including disability. The Equality Act 2010 is one of the most important pieces of legislation in this regard which is supposed to protect disabled people in education and when accessing public services. However, as this research shows, D/deaf people are still not getting their needs met and are suffering as a result. As the BDA argue, the Equality Act 2010 doesn’t adequately address D/deaf people’s health and wellbeing needs by failing to require using qualified interpreters and communication technologies. This has led to D/deaf people being reluctant to seek medical advice and having a poorer understanding of medical treatment. A flaw of this legislation is that it doesn’t recognise BSL and the right to use BSL as being on par with other non-English languages. The focus of legislation is individualistic, prioritising individual rights and protections but making no mention of the value and integrity of BSL and Deaf culture.

Under this act, ‘reasonable adjustments’ must be made by service-providers so that people with disabilities are able to access their services. Service-providers include public services such as schools and healthcare but can also include businesses such as cinemas and restaurants. ‘Reasonable adjustments’ for a D/deaf person or hard of hearing person would be using hearing loop or infrared systems or booking a BSL interpreter so that that person isn’t excluded (Action on Hearing Loss, 2018). The BDA, however, believe that ‘reasonable adjustments’ in the context of D/deaf BSL users is a vague and unclear term. Within education for example, using a communication support worker with a D/deaf pupil is seen as a reasonable adjustment but bilingual English-BSL education isn’t provided. Furthermore, many ‘teachers for the D/deaf’ and classroom assistants don’t have a high level of BSL. Poor access and communication means that the health service is at risk of harming D/deaf patients and isn’t meeting the requirements of the NHS constitution of the equality act (BDA, 2017).

Research Aims

As the existing research has indicated, there exists an inequality in sexual health between the D/deaf and hearing population. Sahir House in its provision of sexual health and HIV support has recognised that there are many barriers in place that restrict D/deaf people from accessing sexual health services and a lack of support specifically for D/deaf people. As one of the main providers of HIV support in Merseyside they have recognised that there is a significant population of potential service-users that could greatly benefit from accessing the services they provide. This research aims to answer:

1. what are the experiences/barriers Sahir House and MSDP staff have in providing sexual health/HIV information to their service-users;
2. what complexities arise from using BSL interpreters and what works best in this field;
3. what barriers D/deaf people have experienced in accessing sexual health services;
4. what other services locally or nationally provide direct HIV and sexual health information and services to D/deaf people;
5. recommendations for best practice in this area.

Methodology

Data Collection

This research project employed a qualitative approach to data collection and analysis. The methods used were focus groups and a qualitative survey. There were 3 focus groups in total, Sahir House staff team, MSDP staff team and Sahir House volunteers. A further qualitative survey was also conducted with a healthcare professional with experience in this field in order to gather recommendations for best practice. All three focus groups were recorded, stored securely on my university M: drive and later transcribed. The qualitative survey involved asking 4 questions via e-mail.

Ethical Considerations

Prior to conducting any data collection, ethical approval was granted by the School of Law and Social Justice department at the University of Liverpool's committee on research ethics. These ethics adhere to the British Sociological Association guidelines on social research alongside the ethical procedure of Sahir House. Sahir House volunteer training was also mandatory as it is for all volunteers, staff, placement students and researchers. This is to ensure that all who work under Sahir House have a progressive understanding of HIV, the effect it has on individuals and what is best practice for working with people who are HIV positive especially considering anonymity and safeguarding service-users. All participants names were removed as well as any information that could be used to identify them. Special attention was made to the safeguarding of D/deaf service-users as belonging to a minority community can make one more easily identifiable.

Debate exists around whether D/deaf people and other disabled groups should be considered 'vulnerable people' and whether this status requires special consideration when being researched. This

is due to the potential for being exploited on the basis of their disability. Within D/deaf culture however, there are debates as to whether deafness is considered and should be considered a disability. There are many D/deaf people who do not consider themselves disabled and reject the idea of them being vulnerable. They instead see themselves as perfectly capable individuals who use a different means of communication. Furthermore, the category of 'disabled' is a fluid and changes in different times and spaces. Likewise, if we do consider D/deaf people as a marginalised group we must also remain conscious of how this marginalisation stems from society at large being a hearing society that is not aware of D/deaf people's needs. As Breivik & Jan-Kåre (2005) argue, D/deaf identities are simultaneously vulnerable at the same time as being highly rewarding, however, this vulnerability relates largely to the pervasive hearing privilege that surrounds D/deaf people's lives.

As a hearing researcher with no prior connection to the D/deaf community I have remained conscious during the research process that my experience and perspective is one that is fundamentally different from the D/deaf experience. I have a duty to represent this community's opinions and perspectives to the best of my abilities making sure that I or any other hearing peers aren't speaking over or erasing their input. As Baker-Shenk & Kyle (1990) argue, it is vital to consider not only the substantive issues and data but also the effect that this data will have on those who have provided it. Standards of ethical conduct in researching D/deaf people are no different than standards for hearing people however, appropriate ethical research practice may require specific awareness and adaptations to regular practice (Young & Hunt, 2011). A hearing person isn't going to have the same experience of existing in a hearing society and so even if they are able to communicate through BSL or an interpreter, they may not understand the speaker on a cultural level. I have remained aware of this throughout the research process and in an attempt to overcome this have immersed myself in aspects of D/deaf culture by learning BSL, reading histories of sign languages and watching various programmes on D/deafness.

Reasoning and Rationale

Qualitative methods for data collection were chosen because it was more appropriate given the purpose of the research. Sahir House had recognised a problem and were concerned with understanding the reasoning behind this problem in an attempt to find possible solutions. As David & Sutton (2004) state, qualitative research is more strongly associated with induction and exploration of social phenomena rather than deductive quantifying of quantitative data. While a quantitative methodology would be appropriate to understand broader trends, research by other organisations has already uncovered statistic information regarding D/deaf people's sexual health needs. Moreover, Sahir House and MSDP had already recognised a problem in their community and were more concerned with understanding its complexities and how to improve the support they could provide.

Qualitative focus groups were used as the primary source of data for this research. Each focus group followed a semi-structured format. This user-led approach was done to emphasise the depth validity of each focus group and an attempt to let the participants tell their own story (David & Sutton, 2004). I attempted to make the questions open ended and to allow for more depth and personal detail. This was appropriate because most participants had years of experience in HIV, sexual health and D/deaf support and this methodology allowed for that experience to be recognised and used to its full potential.

Participants for the MSDP and Sahir House focus groups were employed staff members and so focus groups were the most practical way of gathering numerous voluntary participants and for getting a broader input than compared to interviews.

Narrative techniques were used with the focus groups as participants were asked to describe their experiences working with D/deaf service-users, did they think that the service-user benefited from the service and what barriers did they come across. Experiences with working with Interpreters was also included in this including how they usually work with interpreters, what issues can arise and how are they mitigated. The results from the focus groups were then contrasted with each other.

Data analysis methods

As David and Sutton (2004) state, qualitative data collection and analysis are able to fold into one and other making the distinction between data collection and analysis not as clearly defined than compared to quantitative data. Any attempt to draw meaning from the world can be considered a form of data analysis even if not formally names such. In this research project, data analysis has been used to identify and understand the presence of themes, ideas, beliefs and practices from the data that has been collected. This thematic analysis has involved identifying recurring ideas within the data through coding and developing these ideas into themes to be explored in a wider context. This method was also appropriate for contrast between different data between the focus groups and the qualitative survey as well as other research which has been done on this topic.

Coding is a highly significant aspect of data analysis. It is the identification of common meanings, words, ideas etc. which are then labelled as such every time they reappear. This method was used on focus group transcripts. Recurring ideas and instances were tagged respectively so that they could be compared with each other (David & Sutton, 2004). This allowed for the most important points and topics to be extracted out of the large amount of data in the form of a small number of key themes.

Findings

These themes were identified through analysing and coding of the data collected. I have identified 7 themes although there is significant overlap between them:

1. Generational difference in D/deaf education and welfare
2. Lack of D/deaf awareness
3. Interpretation
4. Inability to be a regular service-user
5. Barriers in accessing sexual health information

1. Generational differences in D/deaf education and welfare

D/deaf welfare and education has changed greatly in the past century. Education and schooling for D/deaf pupils has only recently become mainstream. Before then, most D/deaf education was done through boarding schools and specialist schools for the D/deaf which emphasised teaching D/deaf children to 'fit in' by learning to lip-read and enhance their hearing as much as possible. BSL was seen as something D/deaf adults resorted to if they 'failed learning to speak' (Kyle & Woll, 1985). English literacy was not emphasised and as a result many D/deaf pupils who went through this system do not have a high level of literacy. The phrase 'deaf and dumb' was commonly used which describes the ethos of the time. D/deaf people were assumed to be unteachable and only able to learn basic things. Educational attainment for D/deaf children still remains much lower than their hearing peers although the gap appears to be narrowing (Wilson & Sin, 2015). This generational difference has an effect on sexual health knowledge and accessing sexual health services.

"Back then a lot of hearing people they wouldn't think about teaching the sex education to D/deaf people they think if I teach them this information they are gonna go out and have sex and create more D/deaf people and they don't want that" (MSDP participant)

This participant encapsulates the issue of the time as well as bringing up the belief in disabled people's mandatory asexuality. Historically, disabled groups have been assumed to have no sexual desire and so it is no surprise that their sexual health was rejected (Johnson & Lund, 2015). The welfare of D/deaf people more generally has historically been extremely poor. As well as forced asexuality, a low quality of education for the D/deaf worked to limit their independence and potential and perpetuate inequality. As deafness was perceived as a learning disability it was perceived that educating D/deaf people about sex would lead them to procreate. Inadequate sex education however, isn't exclusive to D/deaf people.

"But I think it's a generational thing, I'm hearing, I went to a mainstream school but I never had any sexual education in school so it wasn't just because they were D/deaf I think it was just the thing not to be done at the time yknow if you didn't teach it you couldn't go on and participate in it" (MSDP participant)

It wasn't until the 70s and 80s that sex education moved from a scientific biological account of sexual reproduction and towards fuller accounts of the human reproductive system along with contraception methods (Reiss, 2005). As the Ofsted 'Not Yet Good Enough' report indicates, sex and relationship education has improved but young people are still being left unprepared for the complexities of sexual and romantic relationships.

Misinformation within the D/deaf community came up as a problem that MSDP have had in supporting their service-users. For example the AIDS campaigns that were not made accessible to D/deaf people as a result, many D/deaf people at the time may not have been educated about HIV/AIDS, only understanding that AIDS equals death. This discourages potential D/deaf service-users from accessing support.

"you might get times where someone won't understand so you see a grave with a cross on it, what's that? Is it death? Oh right, that's what it gets labelled with. One of my clients said "Sahir House, I won't go" I said why? He said, "cos it's a death house"" (MSDP participant)

Older generations of D/deaf people may be less educated when it comes to sexual health particularly HIV and the LGBT community.

"A lot of the older generation think, I'm alright cos I'm straight, I'm married or I'm with a girl I can't get anything, they only think that if- you can only catch things if you're gay which to them is dirty so a lot of it again is because of the lack of education" (MSDP participant)

"Our older generation of the D/deaf community they're not aware, they see obviously people who might be gay, lesbians they see groups they exclude themselves from that sort of group, they don't want anything to do with them, "I wouldn't be anywhere near that" but it's just lack of awareness" (MSDP participant)

Another example of miscommunication is around the term 'HIV positive'. One participant recalled supporting a D/deaf service-user who didn't understand how being HIV positive was a bad thing because 'positive' meant the same thing as 'good'. This confusion is also addressed in a short film made by the D/deaf charity Sign Health (2018) to raise awareness of STI testing. One character raises the same question "But HIV positive...doesn't that mean it's good?". This example illustrates how basic sexual health information isn't reaching D/deaf people and in supporting D/deaf people these complexities must be considered.

2. Barriers in accessing sexual health information

Literacy levels are one reason for a low understanding of sexual health. There is a lack of data on English proficiency in the D/deaf community however the 2011 census for England and Wales found that 65% of BSL users could not speak English or speak English very well. Data on reading ability is dated with the most recent research being from the 90s. Conrad (1979, cited in Wildon & Sin, 2015) found that the average reading age for a D/deaf school leaver to be just under nine years old. Furthermore, Watson et

al. (1999, cited in Wilson & Sin, 2015) found that basic levels of literacy within the D/deaf community are relatively low.

Avenues for accessing information about sexual health overwhelmingly rely on the ability to read English with many D/deaf people being unable to access this information in their language of preference, BSL. Online information and leaflets aren't accessible for all generations of D/deaf people because it is overwhelmingly in English.

"It also depends on one, whether they know where to access, how do they find out these things because they can't look in a newspaper or look on the internet because they don't have that access they might not have that ability to read that well" (MSDP participant)

Online sexual health resources are useful because there is a wealth of information available and allows the participant to learn in privacy, avoiding the embarrassment of having to ask questions in person.

"It's also down to leaflets as well if we were to give a leaflet to a D/deaf person they would literally do as I'm doing now they would open up the leaflet flip it round once or twice have a look at it, go completely over their head" (MSDP participant)

Leaflets are a useful resource in this same regard however, leaflets which are text heavy and contain little to no visual aids are not accessible for all D/deaf people. D/deaf people have varied degrees of literacy so leaflets and online resources may be accessible to some D/deaf people but not all especially the older generation.

"Maybe having a DVD and the DVD consists of all the information on that leaflet but signs onto a video so the deaf person wants that information and rather than taking a leaflet they take a DVD, put it in, they can watch it or, use more pictures in the leaflets" (MSDP participant)

What is more accessible would be have a video and DVD of someone signing the relevant information in BSL. Online videos in BSL online exist but still require the ability to access the internet and know where to look and to be proactive in looking them up. Local dialects are also important to consider as any resource that has a lot of regional signs won't necessarily translate well across the whole country and therefore won't be accessible.

A low level of sexual health knowledge can lead to potentially risky sexual behaviour and an increased risk of contracting STIs due to a lack of understanding of how disease is transmitted and the importance of using barrier contraceptives.

"Some people obviously they might have been raped but they actually think it was S&M but not having that understanding of oh no, this is what's gone on but they just thought it was a way of having enjoyment cos they don't have that understanding" (MSDP participant)

This hypothetical example is very similar to a case study from Deaf@x's EARS research which illustrates how a D/deaf person with low sexual knowledge may not understand the difference between rape and S&M. In this example a young woman wasn't taught any sexual education at school or elsewhere.

Coincidentally, when she was raped didn't understand the ramifications of what had happened and was repeatedly taken advantage of (Deaf@x, 2012). Bodily autonomy and sexual violence are also very important issues that should be considered as a part of sexual health. Not understanding can lead to exploitative situations and have a real effect on D/deaf people's wellbeing.

3. Lack of D/deaf awareness

Many barriers that restrict D/deaf people from accessing sexual health services are unfortunately a result of a lack of D/deaf awareness. D/deaf awareness refers to a knowledge and awareness of the terms and characteristics of deafness, what it means to be D/deaf, how D/deaf people communicate and what is best practice when communicating and working with D/deaf people. From a service-providers perspective, to be highly D/deaf aware would be to understand how a D/deaf person would access their service and what provisions they would need so that they were able to access the service fully. To not be D/deaf aware is to not consider or care how a D/deaf person would access a service, to be unaware of their needs and to not take any special measures to account for their needs. It is clear from this research and elsewhere that a high lack of D/deaf awareness is creating barriers for D/deaf people's access to sexual health services.

Two important needs specific for D/deaf people are accessing high-quality interpreting services and using visual aids and cues. MSDP staff had numerous examples where these needs were not met and range from a waiting room not having a screen with patient's numbers to no interpreter being booked. Booking a high-quality interpreter is perhaps most important because without which the service-user will not be able to communicate fully with staff. Simply failing to book an interpreter after one being requested displays a large degree of ignorance and a failure to make reasonable adjustments.

"That can make the client quite upset then they can get upset quite easily then they don't understand this person and that's just cos they've found the cheapest option and gone and booked someone who was quite cheap" (MSDP participant)

Furthermore, the D/deaf service-user may not know until they arrive the qualification level of the interpreter and so may not be totally sure whether they are suitable for interpreting complicated medical information. Less qualified or trainee interpreters are cheaper to book however, this can have a negative effect on the D/deaf person because the service-provider has chosen the cheaper option over quality indicating that saving money is more important than their welfare. This can upset the service-user and discourage further access. Referrals between different medical departments can also cause problems when the need for an interpreter isn't communicated between departments and so the D/deaf service-user arrives at an appointment without an interpreter. In such cases, staff that know some BSL can offer to help not understanding that being able to interpret at a high level is a very specialist skill that takes years of training they likely don't have. The importance of booking a high-quality interpreter isn't made a high enough priority.

“I’d called up and explained that but they just didn’t book an interpreter, I don’t know why. The nurse came through and said, “oh I can sign a little bit” but you can’t do that, it’s not good enough” (MSDP participant)

““she’s got D/deaf parents, she can sign”, the cleaner comes in! because she’s got a D/deaf aunty and [frustrated sign] “oh it’s alright the cleaner, the cleaner can sign she’s got a D/deaf aunty we know she can sign” is our interpreter?!” (MSDP participant)

These examples illustrate how a lack of understanding of the needs of D/deaf people regarding interpreting services aren’t being met.

4. Interpretation

Sign language interpretation involves listening to someone speak English and conveying the same meaning and message in BSL and vice versa. High-quality interpretation is an important factor in how much D/deaf service-users will benefit from the service.

“So with whether it’s a signer or a language interpreter, you’re involved with a third person in the discussion...so you’ve got to try and acknowledge the embarrassment of somebody that’s used to translating stuff that could just be yknow filling in a form suddenly gets involved in some quite explicit sexual conversation” (Sahir House participant)

Complications arise from discussing sexual health which can be a very private matter. When using an interpreter, a third party is being introduced to what is usually a 2 way conversation. The service-user must trust that the interpreter is conveying the exact meaning that they are communicating and that they safeguard that information. For the interpreter, they may not be adequately equipped to interpret in a sexual health setting because of the particular needs regarding safeguarding of information and mitigating embarrassment.

“Sometimes you have to trust that they’re making the right signs but also, they’re not giving over some of their attitudes or their beliefs or whatever yknow it’s a very difficult thing to do with some particularly with someone talking about sex, I think there has to be a lot of trust and a lot of openness I s’pose” (Sahir House participant)

“Now I know interpreters are bound by confidentiality, codes of ethics that they follow they’ve got to stay confidential but you can still have some D/deaf people who at the back of their minds, will they actually be confidential? Because what I’m about to discuss is really private” (MSDP participant)

Trust became a recurring theme in both staff focus groups. Anxieties over whether one’s information will remain confidential is a barrier that restricts potential service-users. HIV status for example, is a highly private matter that carries stigma. Belonging to the D/deaf community can complicate issues of anonymity as D/deaf individuals may feel that they are more identifiable. As well as trusting in the

interpreter to maintain confidentiality, the D/deaf service-user and the staff member must both trust that they interpret the information accurately.

“We live in a society that default to prejudice around HIV so I’m gonna be a little bit suspicious, the suspicious might sound a bit loaded but because that’s the reality, so that trust in exercise that you as a translator are gonna say to that public that HIV is transmitted in x, y, and z way and not gonna say gay sex, gay men, black Africans cos I haven’t said that” (Sahir House participant)

Interpreters are still people. The prejudice and misinformation found in the general public can also be found in interpreters. Several Sahir House staff recalled experiences working with interpreters with problems like the above. An interpreter’s prejudices can lead to them to interpreting information inaccurately as well as inserting their own prejudice. It is a large exercise of trust because the service-provider isn’t aware of what is being communicated exactly and must trust that they are doing their job correctly.

“So it goes two ways it’s not just about us mitigating embarrassment it’s how do those who are paid a lotta money who we have to, yknow it’s a lot of practical faff to book and the rest of it, what efforts are they making to make themselves savvy and aware of the issues and that’s not just us as customers of an interpreting service but all the other customers that they serve” (Sahir House participant)

An interpreter’s discomfort at the information can also impact on their performance as exemplified with one Sahir House staff member’s experience of delivering sexual health training to a D/deaf group.

“We used to always do a session about condoms, how to put a condom on and activities and it was kind of light-hearted and fun and the translators who were sitting next to me would be translating to a point and then they would just [imitates freezing in place] and then the group would start laughing and then the translators would just give up and would follow me” (Sahir House participant)

The D/deaf service-user must also trust that the interpreter won’t judge them for their sexuality or HIV status. Considering the nature of sexual health and HIV, some service-users may have the desire to only work with specific interpreters. From a service-providers perspective this limits the flexibility of their services as it becomes dependent on whether the interpreter is available. The locality of BSL in regional accents also emerged as a theme as an interpreter from Manchester may not fully understand Liverpool sign.

“Like it’s accents, regional dialects things like that it’s the exact same in signs if you have someone out of the area that you live in, you can get someone who’s not gonna understand certain signs” (MSDP participant)

This creates problems when accessing sexual health information via BSL online because the video may contain regional signs that they don’t know or that the D/deaf viewer may only understand their local

sign. This may be less of a problem for younger D/deaf people as research indicates that younger BSL users aren't using as many regional signs (UCL Deafness Cognition and Language Research Centre, 2018).

If the service-provider is responsible for booking the interpreter then the service-user will not know until they arrive whether they know the interpreter and whether they are comfortable with them. This creates further problems when for example, attending an appointment for a female specific issue and a male interpreter is booked. This is also more practical in some cases as the same interpreter is already aware of the current complexities and doesn't need to be updated every time. This arrangement however, relies on the D/deaf service-user to be proactive in their booking.

5. Fitting into services

D/deaf service-users cannot access sexual health services as hearing people do and require certain needs to be met such as the use of an interpreter. Because of this they are unable to access sexual health services without some degree of forward planning. This excludes them from the 'drop-in' model of sexual health testing which allows for anonymity and quick access. D/deaf people are therefore less likely to access services casually such as a non-symptomatic sexual health screening. These conditions can lead to D/deaf people accessing sexual health services in crisis or when a more serious problem or symptom has arisen which is harder to solve.

"In a way there's a lot of planning, it's like a lot of forward planning whereas other people can, as you say, fit into services, this has to be planned a lot in advance and then if it happens to be a bad day for that person..." (Sahir House participant)

"Sometimes they wouldn't attend appointments and you'd have an interpreter who you're paying for and nobody there to interpret with and other times they would turn up in crisis or with some issue unplanned and very difficult to manage that so having to resort to pen and paper or if you're lucky enough to have a member of staff with limited signing ...but it could be quite a challenge" (Sahir House participant)

If a service-user is supposed to attend an appointment but turns up late or has to cancel, the service-provider can try and fit them in later on or soon after. For a D/deaf service-user needing an interpreter however, they are unable to be as flexible because it is dependent on whether they can get another interpreter at short notice. This problem is exacerbated even further if the service-user will only work with one specific interpreter. This can lead to frustrations in all parties which can discourage the service-user from returning.

"They can't access the service unless they have interpreters there, there is no other way of them to do it, the first point of call when they do arrive is well how do i ask for an interpreter?" (MSDP participant)

Even if the service-provider can book a high-quality interpreter, there is going to be difficulty in arranging an appointment if the first point of call isn't able to communicate with the D/deaf person. This

is sometimes done through filling out a form however this isn't an ideal means of communication for all D/deaf people.

Discussion

The Austerity measures that have been rolled out since 2010 have had a disproportionate effect on the disabled population (BDA, 2017). Interpreting services have suffered a negative impact of austerity with many public bodies opting for cheaper interpreting services and booking unqualified or trainee interpreters or those with only a basic certificate in BSL (Anonymous [BSL interpreter], 2016). Such provisions are unable to explain the intricacies of conditions like HIV, the effect it has on the body and how the client is feeling. To understand how sexual health services are not meeting the needs of D/deaf people one must consider the wider welfare and political context.

D/deaf people can experience multiple levels of prejudice stemming from living in an ableist, homophobic, racist and stigmatising society which creates intersections that can inform their choices in sexual health. Drug and alcohol dependency, social isolation and precarious living conditions are all issues which intersect with being D/deaf to create complex sexual health needs. Whilst D/deaf people face barriers stemming from living in a hearing world there are other factors which are related to, but not exclusive, to being D/deaf. It is important to remember that D/deaf people are a diverse population with diverse opinions, preferences and needs. D/deaf people have varied levels of hearing ability and so technologies such as hearing loops may be useful for some but not all. Support services for D/deaf people need to take this into account and recognise that there may be issues outside of their deafness that need to be counted for. Being D/deaf in a hearing society doesn't inherently make someone vulnerable but existing in a hearing society can exacerbate problems and lead some individuals down paths of dangerous and risky behaviour. Particularly regarding sexual health and sexuality, confidentiality and the D/deaf community needs to be of the utmost importance.

Recommendations for best practice in the area

D/deaf awareness

Many problems outlined in this report are a result of a lack of awareness of the needs of D/deaf people. In particular, the need for high-quality interpreting services. People working in sexual health must be aware of these needs so that they can ensure that D/deaf people receive the same high-quality treatment that hearing people do. An awareness needs to be maintained regarding the complexities of belonging to the D/deaf community and the issues around anonymity and confidentiality that comes with that. Because of this, special measures should be taken with the service-user, staff and interpreter to maintain confidentiality. While there needs to be nationwide shift towards D/deaf awareness, change can begin at this level. Those outside of the D/deaf community rarely have any competency in sign languages but just by learning some basic signs a D/deaf person can be made to feel much more welcome and build a positive relationship. This is especially important for reception staff as they are the first point of call.

As recommended by SignHealth, set clear standards for access to services by D/deaf people so that providers and patients are aware of what is expected and acceptable (SignHealth, 2014). The service-user's communication preference should be noted and respected. Build D/deaf awareness into assessment procedures and assist staff to be aware of individual needs. Needs assess your organisation and find out if its D/deaf friendly, possibly invest in technology that would be more accessible for D/deaf people but also people with other communication difficulties.

Further research into interpreter training and interpreter guidelines

Further research is needed into the training (if any) that BSL interpreters receive regarding interpreting information about sex, sexual abuse, HIV and other sensitive topics. A Sahir House staff member when working with interpreters makes sure to get in touch beforehand and share with them the program, handouts etc. so that they understand what is sometimes intricate clinical information and that they have a progressive awareness of HIV.

The measures that this staff member takes ensure a high-quality of interpretation however the question of whose responsibility is it do this. For a sexual health professional to do this would suggest that there is a significant enough worry over whether the service they are paying for is of a high enough quality. Research into other sexual health services and their guidelines for booking interpretation could prove useful. For example, RASA Merseyside, how do they use language interpreting services for survivors of sexual assault? Do their interpreters need to have specific training or experience and if so where is this training offered?

Research into interpreting options

Because of technological advancements interpretation can be done in several different ways. Under the 2010 Equality Act service-providers have to provide reasonable adjustment for D/deaf people when accessing services. In the case that an interpreter is not available in person or a D/deaf service-user turns up in crisis, online BSL interpretation is available through services such as InterpreterNow and

SignVideo for example. These options should be available for the service-user to choose from if they think that it is the best option. Online video interpretation isn't a substitute for an in-person interpreter but it may be preferable to some if they feel it gives them more anonymity. Before this service is offered however, an organisation should risk assess and consider which service is most appropriate for them and the service-user's needs especially regarding anonymity and confidentiality. The service-user should have the option to choose how they communicate as 'reasonable adjustment' is defined by the service-user.

Advertise as D/deaf friendly & D/deaf outreach

Sexual health services need to make adjustments to the specific needs of the D/deaf community. It is clear that there is misinformation within the D/deaf community about HIV and accessing sexual health support. This misinformation and lack of understanding will need to be overcome to get more D/deaf people accessing sexual health support. D/deaf organizations are integral to this as they can signpost to relevant sexual health services and assist their D/deaf service-users in booking appointments, interpreters and calming any anxieties that they may have beforehand. Visual posters and leaflets could be used specifically for D/deaf people to advertise sexual health organizations and to make it clear that the staff have received D/deaf awareness training and understand their needs.

More robust links with the D/deaf community and sexual health services

A service-user focus is necessary to understand the requirements for D/deaf people. The D/deaf community should be consulted with to understand which issues are the most pressing and in need of being provided. It was suggested that key figures in the D/deaf community or within D/deaf organizations could be used as peer mentors to mitigate the barrier between organizations. D/deaf organizations also need to address this problem and actively engage with sexual health professionals and organizations because they both have a specialism the other can learn from.

More robust links between D/deaf organizations, D/deaf clubs, sexual health organizations, sexual health nurses and other relevant organizations such as RASA and WHISK are needed. A multidisciplinary forum of professionals can be established with a mutual interest in developing their understanding of the accessibility needs of D/deaf people. Moreover, mutually benefitting relationships can be built through providing each other with training and services in their speciality in return for the same in their respective speciality.

Conclusion

This research project was aimed at understanding the barriers and issues D/deaf people face in accessing sexual health support services. Upon completing this research, I can conclude that sexual health services are not equipped to meet D/deaf people's needs. It cannot be assumed that D/deaf people have the same sexual health needs as hearing people therefore, when providing sexual health support to D/deaf people an awareness of this must be maintained. Using an interpreter is often necessary to access services but pose specific issues. To deliver HIV and sexual health information they too must have a progressive understanding of HIV and not reinforce many of the pre-existing biases found in the general public. The staff of MSDP were not short of examples where a lack of D/deaf awareness was impeding the support of their service-users.

Deaf people should not be denied the right to equal sexual health support but unfortunately, society disables D/deaf people by failing to provide equal access to services, information and education, which hinders D/deaf people's ability to make informed choices and be fully included in services. Organisations need to ensure that they have clear guidance for staff to ensure that they are D/deaf aware and act on this awareness.

Public health campaigns often use an evidence based approach firstly recognising an issue in health inequality before rolling out a program or campaign to reduce said inequality. This research project offers qualitative evidence towards a growing body of research exploring D/deaf people's health inequality. My hope in the publication of this report is that D/deaf people's sexual health needs are recognised and addressed as an unacceptable inequality today.

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Appendix

Deaf or deaf?

The distinction between how the word D/deaf is spelled out is one that distinguishes a cultural identity to a medical category. deaf (with a small d) is more often used to describe the medical understanding of deafness as something that is an abnormality, the loss of an ability which is necessary for a 'normal life'. Deaf (with a capital D) is used to describe a cultural identity used by those who have a strong identification with their Deaf community. Those who identify as deaf may mainly communicate orally or through sign supported English and may not consider being deaf as a large part of their identity. Deaf individuals on the other hand, would be more likely to use BSL as their first language and would have a strong identification with Deaf culture, people and politics.

This distinction is highly important considering the history of disability politics and civil rights movements. Deaf is an opposition to a medical understanding of deafness and seeks to redefine deafness as a cultural-linguistic minority group with a positive identity. One may identify as Deaf in the same way one identifies with other cultural-linguistic groups such as Welsh or Polish (Young & Hunt, 2011). Unlike 'deaf', one is not labelled as Deaf by medical gatekeepers which gives them greater agency over their own identity.

For this research, I've attempted to be conscious of both identities and so throughout this report and in the research process I've used the abbreviation 'D/deaf' (pronounced as normal). This has been done to create a piece of research which is more inclusive to the diversity of D/deaf people by recognising that there is no one way to 'be deaf' (Young & Hunt 2011).

Services that provide direct HIV and sexual health information and services to D/deaf people

As noted in the research aims I have compiled a list of resources related to sexual health support for D/deaf people. Currently there are no local sexual health support services in Merseyside specifically for D/deaf people however a number of organisations have recognised this need and offer resources online.

- Sign Health - an organisation focussed on alleviating health inequality felt by D/deaf people. Provided the first study of the health outcomes of D/deaf people in the UK titled 'Sick Of It'. Their website includes a great deal of physical and mental health information including HIV, consent, relationships, pregnancy and abortions. All information is available online in BSL. They also provide guidelines for healthcare professionals on how to support D/deaf clients. Sign Health also owns the social enterprise 'InterpreterNow', an app which provides online interpreters so D/deaf people can access public services at no cost. Available at: <https://www.signhealth.org.uk/>
- Deaf@x - an organisation focused on specialist D/deaf-friendly training and resources. As noted earlier produced a research report titled EARS (Education and Advice on Relationships and Sex for deaf people) which can be read online. They have also produced safe sex resources for education and training purposes. A flipbook and DVD in BSL for sexual health signs and a package for teaching/training D/deaf pupils in sex education are available to order online. Available at: <https://www.deafax.org/>
- No Sign of Support - a research report conducted by deaf@x and the British Pregnancy Advice Service contains extensive information about understanding young D/deaf people's sexual health needs. Available at: <https://www.bpas.org/media/1895/no-sign-of-support.pdf>

Data collection details

Table 1 - Sahir House Staff focus group

Number of Participants:	13
Date:	31-02-17
Length of focus group:	50.32

Table 2 - MSDP staff focus group

Number of participants:	8
Date:	23-02-18
Length of focus group:	1hr 17m

Table 3 - Sahir House volunteers focus group

Number of participants:	7
Date:	06-03-18
Length of focus group:	56.39

Table 4 - Qualitative survey

Number of participants:	1
Date:	07-03-18 to 25-03-18
Means of data collection:	E-mail

Participant Information Sheets and Consent forms (overleaf)

Participant Information Sheet – Sahir House staff focus group
D/deaf people’s access to sexual health support and information

Version 3: 16/11/2017

You are being invited to participate in an undergraduate student’s research study on the topic noted above. Please ensure that you have read the information provided in full before giving consent so that you are fully aware of your role as a participant in this study and what the role entails. Please feel free to ask any questions about any part of this information sheet or any aspect of the research. Participation in this study is completely voluntary and you are free to withdraw at any point.

Thank you for reading.

The purpose of this study:

This research is aimed at understanding deaf people’s access to sexual health services and information. Existing literature argues that deaf people have a different experience of sexual health compared to the hearing population and don’t have the same access to sexual health support. This study is researching what specific barriers are in place that restricts deaf people accessing these services. The results of this research will be used to shape the services of Sahir House so that they can better provide services and training to the deaf community.

Why have I been chosen?

You have been chosen to take part in this study because you are an adult, a staff member at Sahir House. 4-10 other MSDP staff or volunteers will be asked to take part.

Do I have to take part?

Taking part in this study is completely voluntary. It is your decision whether you want to take part or not and please don’t feel pressured to take part.

What will happen if I take part?

You will be taking part in a focus group with 4-10 other staff members which will be conducted by Gethin Watkins and facilitated by Serena Cavanagh. Gethin Watkins is the researcher who will mediate the group and provide the points of discussion. The focus group will only be held once and will last no longer than 30 minutes. The discussion will be recorded so that it may be transcribed afterwards and after it is transcribed the audio recording will be deleted. When transcribing your name will be anonymised as well as any sensitive information which could potentially be used to identify you. Direct quotes may be used in the final report. If you would not like your direct quotes to be used please inform the researcher.

What are the risks?

No serious risks have been identified in taking part in this focus group. The discussion of sexual health may cause embarrassment in some participants. You should consider whether you are comfortable discussing this before taking part.

Are there any benefits in taking part?

The results of this research will be used to create a report which may be used by Sahir House to shape their services and training so that they can deliver more inclusive sexual health support services. By taking part in this research you will be a part of this process and if the report is used by Sahir House your client-base will likely benefit from a more inclusive and specialised service.

What if I am unhappy or if there is a problem?

If you are unhappy with this research, or if there is a problem, please feel free to contact the academic supervisor for this research Kay Inckle at 0151 794 3021 and we will try and help. If you remain unhappy or have a complaint you feel you cannot come to us with then you should contact the Research Governance Officer at ethics@liv.ac.uk. When contacting the Research Governance Officer please provide details of the name or description of the study (so that it can be identified), the researcher involved, and the details of the complaint you wish to make.

Will my participation be kept confidential?

Every participant's response will be anonymised. All data collected will be stored on the researcher's university M: drive. The audio recording will be transcribed into text and once transcribing is complete the audio recording will be deleted. The report will not include any names or information that could be used to identify any participants. The transcript will be analysed and used to create the report. After the audio is transcribed individual responses will be unable to be subtracted. If you would like your response to be subtracted please let the researcher know as soon as possible. Special care must also be taken to maintain the confidentiality of the other participants and your client-base.

What will happen to the results of the study?

The results of this research will be used for the creation of an academic report which will be read and graded by academic staff of the University of Liverpool. This report will likely be used by Sahir House.

What will happen if I want to stop taking part?

You are free to withdraw from the study at any point even during data collection. In withdrawing from the study you can also request that your responses will be destroyed however, this will not be possible after the data is anonymised.

Who can I contact if I have further questions?

Any further directions should be directed towards the academic supervisor Kay Inckle at kay.inckle@liverpool.ac.uk and 0151 794 3021 or Gethin Watkins at hsgwat2@student.liverpool.ac.uk.

Participant Information Sheet – MSDP focus group

D/deaf people's access to sexual health support and information

Version 1: 15/11/2017

You are being invited to participate in an undergraduate student's research study on the topic noted above. Please ensure that you have read the information provided in full before giving consent so that you are fully aware of your role as a participant in this study and what the role entails. Please feel free to ask any questions about any part of this information sheet or any aspect of the research. Participation in this study is completely voluntary and you are free to withdraw at any point.

Thank you for reading.

The purpose of this study:

This research is aimed at understanding deaf people's access to sexual health services and information. Existing literature argues that deaf people have a different experience of sexual health compared to the hearing population and don't have the same access to sexual health support. This study is researching what specific barriers are in place that restricts deaf people accessing these services. The results of this research will be used to shape the services of Sahir House so that they can better provide services and training to the deaf community.

Why have I been chosen?

You have been chosen to take part in this study because you are an adult, a staff member or volunteer at the Merseyside Society for Deaf People (MSDP). 5-10 other MSDP staff or volunteers will be asked to take part.

Do I have to take part?

Taking part in this study is completely voluntary. It is your decision whether you want to take part or not and please don't feel pressured to take part.

What will happen if I take part?

You will be taking part in a focus group with 5-10 other MSDP staff and volunteers which will be conducted by Gethin Watkins and facilitated by Serena Cavanagh. Gethin Watkins is the researcher who will mediate the group and provide the points of discussion. The focus group will only be held once and will last between 50 to 90 minutes. The discussion will be recorded so that it may be transcribed afterwards and after it is transcribed the audio recording will be deleted. When transcribing your name will be anonymised as well as any sensitive information which could potentially be used to identify you. Direct quotes may be used in the final report. If you would not like your direct quotes to be used please inform the researcher.

What are the risks?

No serious risks have been identified in taking part in this focus group. The discussion of sexual health may cause embarrassment in some participants. You should consider whether you are comfortable discussing this before taking part.

Are there any benefits in taking part?

The results of this research will be used to create a report which may be used by Sahir House to shape their services and training so that they can deliver more inclusive sexual health support services. By taking part in this research you will be a part of this process and if the report is used by Sahir House your client-base will likely benefit from a more inclusive and specialised service.

What if I am unhappy or if there is a problem?

If you are unhappy with this research, or if there is a problem, please feel free to contact the academic supervisor for this research Kay Inckle at 0151 794 3021 and we will try and help. If you remain unhappy or have a complaint you feel you cannot come to us with then you should contact the Research Governance Officer at ethics@liv.ac.uk. When contacting the Research Governance Officer please provide details of the name or description of the study (so that it can be identified), the researcher involved, and the details of the complaint you wish to make.

Will my participation be kept confidential?

Every participant's response will be anonymised. All data collected will be stored on the researcher's university M: drive. The audio recording will be transcribed into text and once transcribing is complete the audio recording will be deleted. The report will not include any names or information that could be used to identify any participants. The transcript will be analysed and used to create the report. After the audio is transcribed individual responses will be unable to be subtracted. If you would like your response to be subtracted please let the researcher know as soon as possible. Special care must also be taken to maintain the confidentiality of the other participants and your client-base.

What will happen to the results of the study?

The results of this research will be used for the creation of an academic report which will be read and graded by academic staff of the University of Liverpool. This report will likely be used by Sahir House.

What will happen if I want to stop taking part?

You are free to withdraw from the study at any point even during data collection. In withdrawing from the study you can also request that your responses will be destroyed however, this will not be possible after the data is anonymised.

Who can I contact if I have further questions?

Any further directions should be directed towards the academic supervisor Kay Inckle at kay.inckle@liverpool.ac.uk and 0151 794 3021 or Gethin Watkins at hsgwatk2@student.liverpool.ac.uk.

Participant Information Sheet – Health Professionals

Deaf people’s access to sexual health support and information

Version 4: 18/11/2017

You are being invited to participate in an undergraduate student’s research study on the topic noted above. Please ensure that you have read the information provided in full before giving consent so that you are fully aware of your role as a participant in this study and what the role entails. Please feel free to ask any questions about any part of this information sheet or any aspect of the research. Participation in this study is completely voluntary and you are free to withdraw at any point.

Thank you for reading.

The purpose of this study:

This research is aimed at understanding deaf people’s access to sexual health services and information. Existing literature argues that deaf people have a different experience of sexual health compared to the hearing population and don’t have the same access to sexual health support. This study is researching what specific barriers are in place that restricts deaf people accessing these services. The results of this research will be used to create a report which may be used by Sahir House so that they can better provide services and training to the deaf community.

Why have I been chosen?

You have been chosen to take part in this study because you are an adult and a professional in the healthcare sector.

Do I have to take part?

Taking part in this study is completely voluntary. It is your decision whether you want to take part or not. Please don’t feel pressured to take part.

What will happen if I take part?

You will be taking part in a qualitative survey conducted by Gethin Watkins the researcher. You will be given questions to answer and statements for you to give your opinion on. This will be conducted via e-mail. The questions and statements will be related to the research topic. Direct quotes may be used in the final report. If you would not like your direct quotes to be used please inform the researcher.

What are the risks?

No serious risks have been identified in taking part in this survey. The discussion of sexual health may cause embarrassment in some participants. You should consider whether you are comfortable discussing this before taking part.

Are there any benefits in taking part?

The results of this research will be used to create a report which may be used by Sahir House to shape their services and training so that they can deliver more inclusive sexual health support services.

What if I am unhappy or if there is a problem?

If you are unhappy with this research, or if there is a problem, please feel free to contact the academic supervisor for this research Kay Inckle at 0151 794 3021 and we will try and help. If you remain unhappy or have a complaint you feel you cannot come to us with then you should contact the Research Governance Officer at ethics@liv.ac.uk. When contacting the Research Governance Officer please provide details of the name or description of the study (so that it can be identified), the researcher involved, and the details of the complaint you wish to make.

Will my participation be kept confidential?

Every participant's response will be anonymised. No names or identifiable features will be included in the report.

What will happen to the results of the study?

The results of this research will be used for the creation of an academic report which will be read and graded by academic staff of the University of Liverpool. This report will likely be used by Sahir House to shape their services and training to be more inclusive.

What will happen if I want to stop taking part?

You are free to withdraw from the survey at any point however, your response will not be able to be deleted because it will be anonymised.

Who can I contact if I have further questions?

Any further directions should be directed towards the academic supervisor Kay Inckle at kay.inckle@liverpool.ac.uk and 0151 794 3021 or Gethin Watkins at hsgwatk2@student.liverpool.ac.uk.

Participant Information Sheet – Sahir House volunteer focus group

D/deaf people's access to sexual health support and information

Version 3: 16/11/2017

You are being invited to participate in an undergraduate student's research study on the topic noted above. Please ensure that you have read the information provided in full before giving consent so that you are fully aware of your role as a participant in this study and what the role entails. Please feel free to ask any questions about any part of this information sheet or any aspect of the research. Participation in this study is completely voluntary and you are free to withdraw at any point.

Thank you for reading.

The purpose of this study:

This research is aimed at understanding D/deaf people's access to sexual health services and information. Existing literature argues that D/deaf people have a different experience of sexual health compared to the hearing population and don't have the same access to sexual health support. This study is researching what specific barriers are in place that restricts D/deaf people accessing these services. The results of this research will be used to shape the services of Sahir House so that they can better provide services and training to the deaf community.

Why have I been chosen?

You have been chosen to take part in this study because you are an adult, a volunteer at Sahir House. Other volunteers will also be taking part.

Do I have to take part?

Taking part in this study is completely voluntary. It is your decision whether you want to take part or not and please don't feel pressured to take part.

What will happen if I take part?

You will be taking part in a focus group with other volunteers which will be conducted by Gethin Watkins and facilitated by Serena Cavanagh. Gethin Watkins is the researcher who will mediate the group and provide the points of discussion. The focus group will only be held once and will last no longer than 45 minutes. The discussion will be recorded so that it may be transcribed afterwards and after it is transcribed the audio recording will be deleted. When transcribing your name will be anonymised as well as any sensitive information which could potentially be used to identify you. Direct quotes may be used in the final report. If you would not like your direct quotes to be used please inform the researcher.

What are the risks?

No serious risks have been identified in taking part in this focus group. The discussion of sexual health may cause embarrassment in some participants. You should consider whether you are comfortable discussing this before taking part.

Are there any benefits in taking part?

The results of this research will be used to create a report which may be used by Sahir House to shape their services and training so that they can deliver more inclusive sexual health support services. By taking part in this research you will be a part of this process and if the report is used by Sahir House your client-base will likely benefit from a more inclusive and specialised service.

What if I am unhappy or if there is a problem?

If you are unhappy with this research, or if there is a problem, please feel free to contact the academic supervisor for this research Kay Inckle at 0151 794 3021 and we will try and help. If you remain unhappy or have a complaint you feel you cannot come to us with then you should contact the Research Governance Officer at ethics@liv.ac.uk. When contacting the Research Governance Officer please provide details of the name or description of the study (so that it can be identified), the researcher involved, and the details of the complaint you wish to make.

Will my participation be kept confidential?

Every participant's response will be anonymised. All data collected will be stored on the researcher's university M: drive. The audio recording will be transcribed into text and once transcribing is complete the audio recording will be deleted. The report will not include any names or information that could be used to identify any participants. The transcript will be analysed and used to create the report. After the audio is transcribed individual responses will be unable to be subtracted. If you would like your response to be subtracted please let the researcher know as soon as possible. Special care must also be taken to maintain the confidentiality of the other participants and your client-base.

What will happen to the results of the study?

The results of this research will be used for the creation of an academic report which will be read and graded by academic staff of the University of Liverpool. This report will likely be used by Sahir House.

What will happen if I want to stop taking part?

You are free to withdraw from the study at any point even during data collection. In withdrawing from the study you can also request that your responses will be destroyed however, this will not be possible after the data is anonymised.

Who can I contact if I have further questions?

Any further directions should be directed towards the academic supervisor Kay Inckle at kay.inckle@liverpool.ac.uk and 0151 794 3021 or Gethin Watkins at hsgwatk2@student.liverpool.ac.uk.

Committee on Research Ethics

PARTICIPANT CONSENT FORM – Focus Group

Title of Research Project: D/deaf people's access to sexual health support and information

Researcher: Gethin Watkins

Please
initial box

1. I confirm that I have read and have understood the information sheet dated [DATE] for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my rights being affected. In addition, should I not wish to answer any particular question or questions, I am free to decline.
3. I understand that, under the Data Protection Act, I can at any time ask for access to the information I provide and request its destruction and also understand that this may not be possible after it is anonymised.
4. I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any publications.
5. I understand and agree that my participation will be audio recorded and I am aware of and consent to your use of these recording for the purpose of transcribing.
6. I understand that my responses will be kept strictly confidential. I give permission to the researcher to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report that results from the research.
7. I understand and agree that once I submit my data it will become anonymised after which I will therefore no longer be able to withdraw my data.
8. I agree not to disclose any information about a specific person or people's sexual history and not to disclose any features which may be used to identify them. I will take special measures to safeguard my client-base.
9. I agree to maintain the confidentiality of other participants and the client-base of both Sahir House and Merseyside Society for Deaf People.
10. I agree to take part in the above study.

_____ Participant Name	_____ Date	_____ Signature
_____ Researcher	_____ Date	_____ Signature

Principal Investigator:

Name: Kay Inckle

Work Address: University of Liverpool, Bedford Street South, Liverpool L69 7ZA

Work Telephone: 0151 794 3021

Work Email: kay.inckle@liverpool.ac.uk

Student Researcher:

Name: Gethin Watkins

E-mail: hsgwatk2@student.liv.ac.uk

[Version 4. 20/12/17]

Committee on Research Ethics

PARTICIPANT CONSENT FORM – Qualitative Survey

Title of Research Project: D/deaf people's access to sexual health support and information

Researcher: Gethin Watkins

**Please
initial box**

11. I confirm that I have read and have understood the information sheet dated 18/11/17 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
12. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my rights being affected. In addition, should I not wish to answer any particular question or questions, I am free to decline.
13. I understand that, under the Data Protection Act, I can at any time ask for access to the information I provide and request its destruction and also understand that this may not be possible after it is anonymised.
14. I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any publications.
15. I understand that my responses will be kept strictly confidential. I give permission to the researcher to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report that results from the research.
16. I understand and agree that once I submit my data it will become anonymised after which I will therefore no longer be able to withdraw my data.
17. I agree not to disclose any information about a specific person or people's sexual history and not to disclose any features which may be used to identify them. I will take special measures to safeguard my client-base.
18. I agree to take part in the above study.

Participant Name

Date

Signature

Researcher

Date

Signature

Principal Investigator:

Name: Kay Inckle

Work Address: University of Liverpool, Bedford Street South, Liverpool L69 7ZA

Work Telephone: 0151 794 3021

Work Email: kay.inckle@liverpool.ac.uk

Student Researcher:

Name: Gethin Watkins

E-mail: hsgwatk2@student.liv.ac.uk

[Version 3. 20/12/17]