

Conclusions

SRE

SRE is letting down young D/deaf people. They are not given the level of information and education required by the National Curriculum, nor government guidance. As a result many have poor levels of understanding of issues relating to sex and relationships.

A significant minority (16%) of those surveyed said they did not receive SRE in school, and of those who did, the majority missed out on essential information. We call on the government to introduce comprehensive, compulsory SRE to address these failings as a matter of urgency.

It is imperative that young D/deaf people do not miss out on essential information that enables them to understand their bodies, protect their health, and negotiate adult relationships. Teachers and those delivering SRE to young D/deaf people should be mindful of communication barriers. They should ensure that there is necessary communication support during lessons and that resources used are D/deaf friendly.

We fully appreciate the demands placed on schools' timetables. However, it would benefit many young D/deaf pupils if additional time was allocated to SRE lessons to ensure they are able to fully understand the topics. The vast majority of young D/deaf people are in mainstream schools, and the different levels of awareness compared with other pupils should be taken in to account. If extra time was provided for D/deaf students, who may have a lower level of understanding because of difficulties accessing information outside of the classroom, this could significantly improve their understanding of the information given.

Schools would benefit from collaboration with external organisations providing specialist resources and lessons for D/deaf pupils. This would be a useful and practical way to ensure the delivery of accessible SRE.

Sexual and reproductive healthcare services

Young D/deaf people are unable to access sexual and reproductive healthcare services when they need to. Organisations must urgently address this problem and ensure that they are able to support all young people, regardless of additional needs. It is important that they fulfill their obligations set out in the Equality Act 2010.

To help healthcare providers improve their services, better data collection around the number of D/deaf service users may be useful. Current figures are woefully out of date with, for example, the most recent statistics for the numbers of D/deaf women accessing maternity care collected over 20 years ago.²⁷ More recent figures could provide healthcare services with a stronger basis from which to plan their services, and also challenge the invisibility of D/deaf people and their needs.

Healthcare professionals need greater opportunities for training in D/deaf awareness. We know that staff want to be able to provide good care for D/deaf patients, and through relatively short training opportunities this can be achieved. For example, at the Deaf Nest maternity care day, the proportion of attendees who felt confident assessing D/deaf women's needs and providing care increased from 25% to 84% and 25% to 87.5% respectively.²⁸ Such training opportunities may be particularly important for staff working in walk-in and emergency services, such as sexual health clinics, who may not be able to arrange communication support on short notice.²⁹

Relatively simple steps, such as healthcare staff collecting patients from the waiting room to ensure they do not miss their name being called for their appointment, are proven to make a significant difference to D/deaf people's experience of accessing healthcare services, as has the provision of D/deaf-friendly ways to book services and

communicate with healthcare professionals such as textphone, SMS, and online chat.³⁰ Training courses could play a crucial role in enabling the sharing of best practice, and encouraging their implementation.

Continuity of care appeared to be particularly important to several of our respondents who had given birth. They stated that they found it difficult to communicate with different midwives at each appointment, findings echoed in other research around D/deaf women's experience of midwifery services.³¹ Providing a D/deaf aware midwife, who is able to provide a personalised service and support individual D/deaf women throughout their pregnancy and birth, may be particularly important to ensure a good quality of care and a positive experience of pregnancy and birth.

Our survey revealed that many young D/deaf people are not provided with communication support and/or accessible information during healthcare appointments. This should not happen. Even if staff are D/deaf aware, it is still important that clients are offered the option of an interpreter to enable full communication, patient choice, and informed consent. Fully relaying and explaining medical information may require additional time, and staff should be aware of this when scheduling appointments.

Organisations need to ensure that they have clear guidance for staff to ensure they are confident in booking interpreters and that the need for communication support does not cause unnecessary delays in accessing treatment. We would also welcome more tools and resources for healthcare professionals, preferably online, to facilitate communication when an interpreter is not present.

²⁷ Sporek, The Deaf Nest Project.

²⁸ Ibid.

²⁹ NHS England (2014), Making Health and Social Care Information Accessible.

³⁰ Ibid, and Royal College of Nursing (2007), Pregnancy and Disability.

³¹ Jackson, M. (2010), 'Supporting Deaf Mothers', Disability, Pregnancy & Parenthood International Vol. 69.

No sign of support

Understanding young deaf people's sexual and reproductive health needs

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Introduction

The D/deaf community experiences higher rates of unplanned pregnancy and STIs than the rest of the population.¹ They are severely disadvantaged when they need to access healthcare services and information, and myths and misconceptions about sex and sexual health are widespread.²

Many young D/deaf people lack the resources and support to enable them to make empowered choices about their sexual and reproductive health. The British Pregnancy Advisory Service (BPAS) is a reproductive healthcare charity which sees nearly 70,000 women a year and, as well as providing services in clinics, has an education programme with a particular focus on young people with additional needs. Deafax is a charity dedicated to using technology to improve literacy and life skills and to reducing the feelings of isolation felt by many deaf people.

BPAS and Deafax surveyed over 100 young D/deaf people and held a sex education session with 20 students to ask them about their experience of sex and relationships education (SRE), their knowledge of sexual health and contraception, and access to these services.

The results suggest that much more needs to be done by both schools and healthcare providers to better support this group of young people.

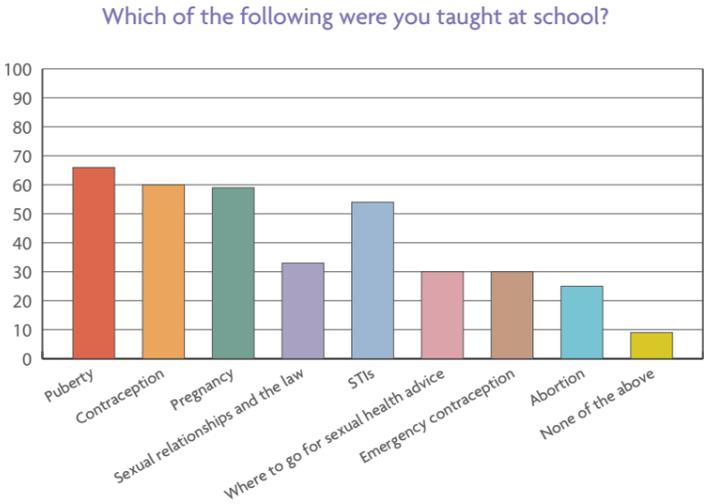
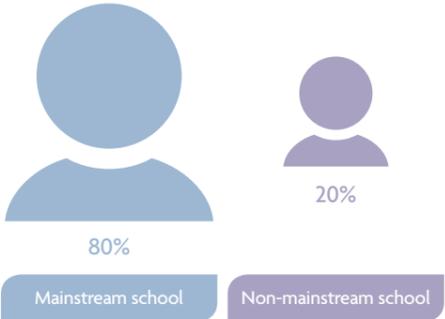
“There have been a lot of communication barriers throughout my life. Not know what I’m supposed to know and finding it all out via family and the media... I avoid medical appointments unless I know I have support in the services.”



SRE

There are nearly 38,000 D/deaf children in England and over 80% attend mainstream schools.³ All maintained secondary schools are required to provide sex and relationships education (SRE), including education about sexually transmitted diseases, and must teach students about the biological aspects of reproduction as part of the national curriculum. At primary school level, puberty should also be taught.⁴

Unfortunately, our survey revealed that young D/deaf people are missing out on the basics in SRE. While the vast majority received SRE lessons at school (84%), one-third said they were not taught about puberty, 40% were not taught about pregnancy, and nearly half (46%) were not taught about STIs – all topics that are included in the national curriculum.



“I didn’t have much support at school so I missed out on a lot, so I am very confused about sex ed.”



“Basic information, but not enough and no examples or show us things like contraceptives.”

While the government recommends that students are given information about preventing pregnancy in order to reduce teenage conception rates, 40% were not taught about contraception.⁵

“I personally think it [SRE] needs updating, needs more specific information and [should cover] the emotional side of sexual relationships.”

Only one third of those surveyed were taught about sexual relationships and the law, and in our SRE session less than half (47%) knew the legal age of consent. The RNID, National Deaf Children's Society (NDCS), and the NSPCC have all identified D/deaf children as having an increased vulnerability to sexual abuse.⁶ The government has also acknowledged that D/deaf children 'seem particularly vulnerable

to abuse', suggesting this may be linked to communication difficulties.⁷ Furthermore, additional research has suggested that gaps in information and understanding put young D/deaf people at greater risk, as they are perceived as less likely or able to report abuse.⁸ It is hard not to draw the conclusion that this group of young people need additional support in SRE.

“[SRE] needs to be improved. Particularly relationships with people younger than you and how this can be illegal and lead to trouble... pupils are not warned or educated.”

Ofsted has raised concerns about SRE provision across the board, stating that it requires improvement in over a third of schools.⁹ However, it is particularly important

that good SRE provision is in place for D/deaf students given the additional barriers they face in obtaining healthcare information outside of the classroom as existing resources are unsuitable. Department for Education figures show that 35% of D/deaf children leave primary school without basic reading skills, compared with 6% of children with no identified special educational needs, and up to 50% of D/deaf students leave secondary school with a reading level of 9-10 year olds.¹⁰

Consequently, many of the young people we surveyed relied on images from online search engines to find out information about sex. This left many still confused and, in some cases, distressed by images which were not suitable for them.

“[I use] Google but don't like, not right, can't understand and sometimes sad and horror.”

Knowledge of sex, contraception and STIs

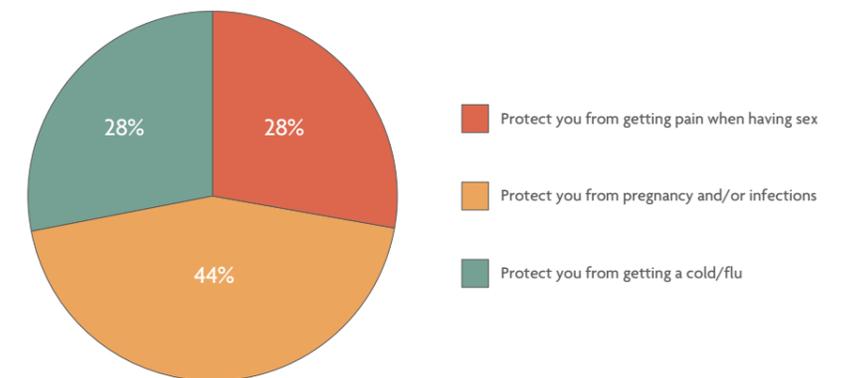
In our SRE session, we found many of the students did not have enough information needed to protect themselves against unwanted pregnancy and STIs.

More than half believed that the role of contraception is to protect you from pain or catching a cold (54%), less than one in ten (6%) were aware of the range of contraceptive options available and only one third (33%) knew where to go to get free contraception.

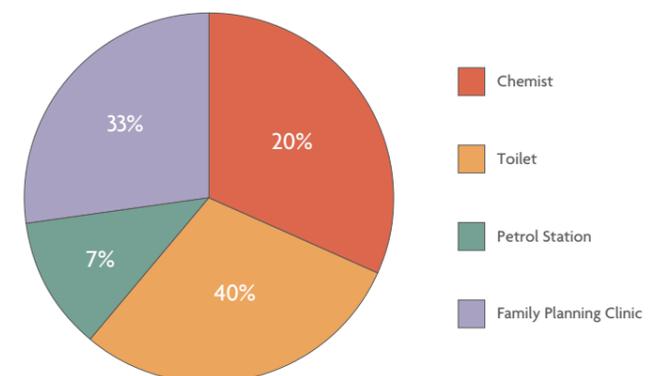
We are concerned that this lack of basic knowledge may prevent these young people accessing services when they need to. As one teacher in the session commented: “How can they ask for contraception if they don't know what it is?”

“The advice about contraception [at school] was limited. It was like, ‘use a condom otherwise you'll get AIDS.’ ”

What do contraceptives do?



Where can you get free contraception?



¹ Parsons, J. (2013), 'Deafness, Pregnancy and Sexual Health', The Practising Midwife Vol. 16, No. 6.

² SignHealth (2014), Sick of It.

³ Consortium for Research in D/deaf Education (2013), Report on 2013 Survey on Educational Provision for Deaf Children in England.

⁴ The Association for Science Education (2014), Teaching About Puberty.

⁵ Department for Education (2000), Sex and Relationship Education Guidance.

⁶ RNID Scotland and NDCS (2008), Response to Mental Health (Care & Treatment) Act Review, and NSPCC (2010), Sex and Relationships Education Guidance Consultation Response.

⁷ Department of Health (2005), Mental Health and Deafness: Towards Equity and Access.

⁸ Harmer, L.M. (2005), 'Health Care Delivery and D/deaf People: Practice, problems, and Recommendations for Change', Journal of Deaf Studies and Deaf Education Vol. 4, No. 2.

⁹ Ofsted (2013), Not yet good enough: personal, social, health and economic education in schools.

¹⁰ NDCS (2008), Every School a Good School: A Strategy for Raising Achievement in Literacy and Numeracy.

¹¹ NIHR School for Social Care Research (2011), Research with D/deaf people.

Why are deaf people being let down by SRE?

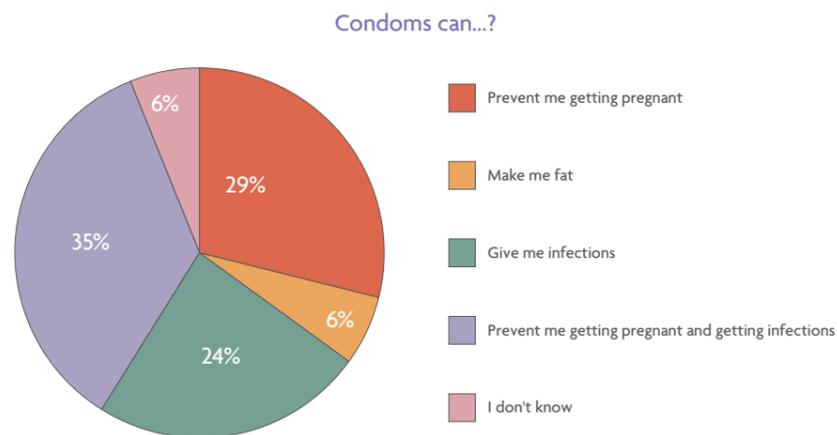
“When someone puts pressure on you to have sex but you say ‘no’ but you don’t want to lose your relationship. I want to know how you can save your relationship.”¹⁴

There are a number of factors at play that prevent young D/deaf people getting the information they need from SRE lessons.

The students’ awareness of STIs was also poor. Only 35% knew that condoms could prevent the transmission of infections, and almost all were not aware of the term STI. Our results mirror those found in a survey of D/deaf people as part of the documentary Snapshot: Dicing With Sex, which found 78% were unable to correctly identify STIs or describe how they were contracted.¹²

Many of our survey respondents felt that they would have benefited from a greater focus on the emotional and social aspects of sex and relationships in their SRE lessons. The government has stated its support for SRE which “stresses the importance of respecting individual autonomy.” However, over half (53%) of the students in our SRE session said that it was acceptable for a partner to say “If you don’t have sex with me, it means you don’t love me”, and nearly a quarter (23%) said they thought it was acceptable for a partner to insist that they don’t go out with their friends.¹³

“I personally think it needs updating, needs more specific information and [should cover] the emotional side of sexual relationships.”



Government guidance makes it clear that schools must meet the needs of all pupils, regardless of their sexual identity, yet several survey respondents said that they were not taught about same sex relationships, leaving them feeling isolated and confused.¹⁵ This echoes recent research which found that 85% of gay and bisexual men said they received no information about same sex relationships at school.¹⁶

“Don’t feel enough info for gays. Nothing at school level to help. Feel can’t say. Feel alone.”

Sadly, it appears that many young D/deaf people are missing out on the government’s stated vision of SRE preparing pupils for the challenges and responsibilities of adult life.

Our survey revealed problems with the delivery of SRE. Several respondents stated that the information was not presented in an accessible way, such as videos without subtitles or written resources with words they did not understand, and that a more visual approach would have been more effective.

“Need more visual demonstrations to ensure D/deaf kids understand clearly.”

Respondents also said they were not given adequate communication support during SRE lessons. It is unclear from our survey why support was not provided to pupils, although the charity NDCS has previously raised their concerns about the availability of specialist support services for D/deaf children in school and the affect this might have on their educational achievement.¹⁷

“There was no access for D/deaf information such as BSL, interpreter, D/deaf friendly, etc. I didn’t learn a thing at school [about SRE].”

However, even when communication support is provided during the lessons, a lack of time to fully communicate the content can be problematic.¹⁸ This appears particularly pertinent with regards to SRE, as many young people lack the basic vocabulary around the topic, and therefore it is vital that sufficient time is given not just for relaying but also explaining information.

“The problem when the interpreter is processing the information is how do they translate it? What do the students know? A new word – eg STD – is just relayed. But then there’s a gap. I need the teacher to stop so I can explain. But that means the hearing pupils would have to wait and get bored.”¹⁹

The students we spoke with seemed to benefit greatly from questions being acted out rather than simply given to them in written format. Again, this requires additional time, which many teachers just do not have.

“[To explain the information] I have to use a lot of drama, or internet clips, but I don’t really have time do all this.”

Over 80% of D/deaf children of school age are in mainstream school. It is vital that they are given adequate communication support and that reasonable adjustments are made to ensure they are able to understand and participate in lessons, just like any other pupil.²⁰

“Both middle school and grammar school did it by way of showing videos – none of which were captioned.”

¹² Remark Media (2010), Snapshot: Dicing with Sex.
¹³ Department of Education (2010), The Importance of Teaching: the Schools White Paper.
¹⁴ Remark Media, Snapshot: Dicing with Sex.
¹⁵ Department for Education (2000), Sex and Relationship Education Guidance.
¹⁶ Public Health England (2014), Promoting the Health and Wellbeing of Gay, Bisexual and Other Men Who Have Sex with Men.
¹⁷ NDCS (2010), Hands Up for Help.

¹⁸ Remark Media, Snapshot: Dicing with Sex.
¹⁹ Ibid
²⁰ CRIDE, Report on 2013 Survey.

Accessing healthcare services

“Wish sign language at clinics and also to have deaf people working there. Can relate and understand.”

Whilst the vast majority (93%) of students at our school session knew they should go to their GP or family planning clinic if they have unprotected sex, there are barriers that might prevent them from doing so.



Young D/deaf people also said they were more likely to use search engines on the internet than go to a sexual health clinic if they had a problem.

“No way go to the healthcentre. No signing. No deaf people.”

“No provision is made for hearing impaired people at my local clinic. A five digit patient number is called out which is difficult to understand.”

Nearly half of those we surveyed said they did not know where their nearest sexual health service is, and less than a third (30%) were taught about where to go for sexual health advice at school.

The Equalities Act 2010 states that service providers must make reasonable adjustments to ensure that D/deaf people are not at a disadvantage. Yet from booking appointments to communicating at appointments to understanding their medication, many D/deaf people experience difficulties every step of the way.²¹

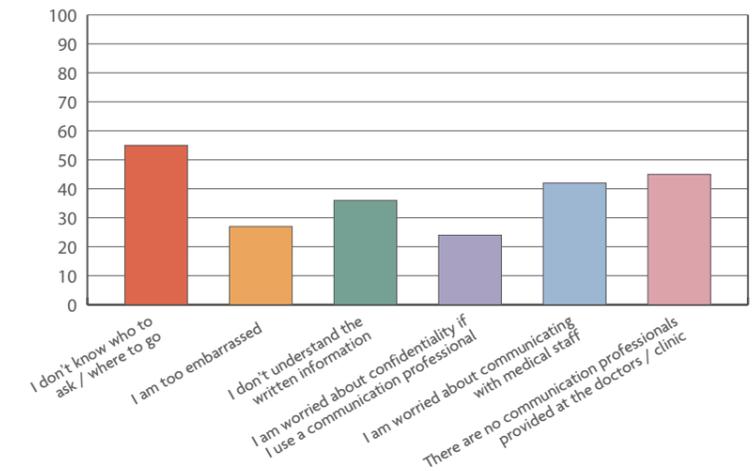
A recent survey by the charity Sign Health found that 70% of D/deaf people who hadn't

been to their GP recently had wanted to go, but didn't, mainly because there was no interpreter.²² Problems around communication also appear to be a significant issue for young D/deaf people accessing the sexual and reproductive healthcare services they need.

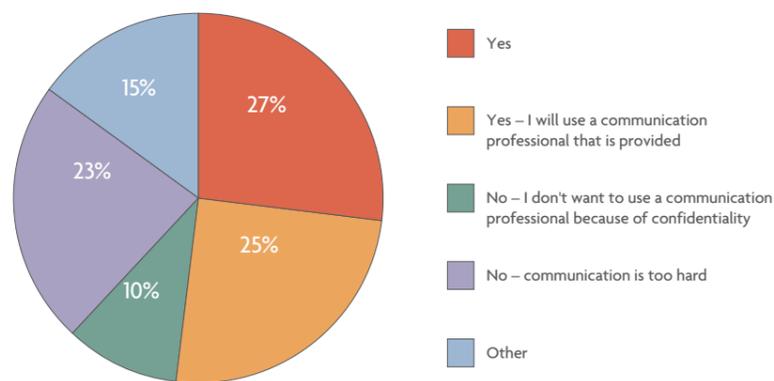
Nearly half (42%) of those we surveyed said worries about communicating with medical staff would stop them getting the information they need about sex and pregnancy, and over a third (36%) raised difficulties understanding written medical information. They also said they were more likely to use internet search engines than go to a sexual health clinic if they had a problem.

Discussing sexual health issues with a medical professional is, understandably, a source of embarrassment for many young people. However, young D/deaf people may have additional concerns because they have previously relied on friends or family members for communication assistance at other medical appointments, or because they are worried about confidentiality when using an interpreter. It is therefore important that service providers are able to arrange professional interpreters and give reassurance that all information will be treated in confidence.

What stops you from getting the information you need about sex and pregnancy?



Do you feel happy going to a clinic for advice about pregnancy or sex?



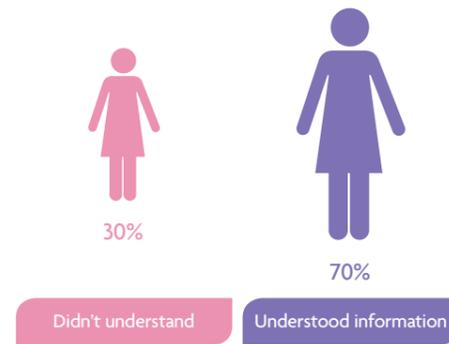
“Sometimes, when I have loss of confidence [about] sex or body something, I can't go to GP for help, because there is no provided interpreter.”

“Yes go [to sexual health clinic] but how get sign support? I not work. No interpreter. What do?”

“I will use an interpreter, but depends on the situation – if it was for a testing, then probably not.... This is purely due to avoiding a third party involvement on personal information.”



Pregnancy



“Antenatal classes have no funds for interpreters, therefore the classes are not clear to follow. There needs to be more support for mothers-to-be in midwife appointments and after the birth.”



“It went smoothly as possible. The hospital I went to was really good in terms of communication, was able to provide me an interpreter whenever I needed it although I declined as the staff were D/deaf friendly.”

“I have 5 children. I got pregnant at 18. Not know what happen to me. No experience or knowledge. I not go to classes and end up give birth on lounge floor. I go on to have more children. I never have interpreter... At hospital scared. Not understand what happening and who people are. They do things to me and not talk about why. At home I get know midwife and have same one for the whole time. At hospital they keep changing.”



“I had a home birth with a lovely small (NHS) midwife team and I chose this largely because I did not feel my deafness would be taken into account if I went into hospital. I did not think staff would have the time or experience to communicate with me properly.”

One third (34%) of the women we surveyed had been pregnant, of whom almost half (48%) had previously had an abortion. The experience of this group of women mirrors that of D/deaf people accessing healthcare services generally, with almost half stating that they did not understand all the information at medical appointments as no communication professionals were on hand. Of those women who had an abortion, 70% felt they understood all the information provided.

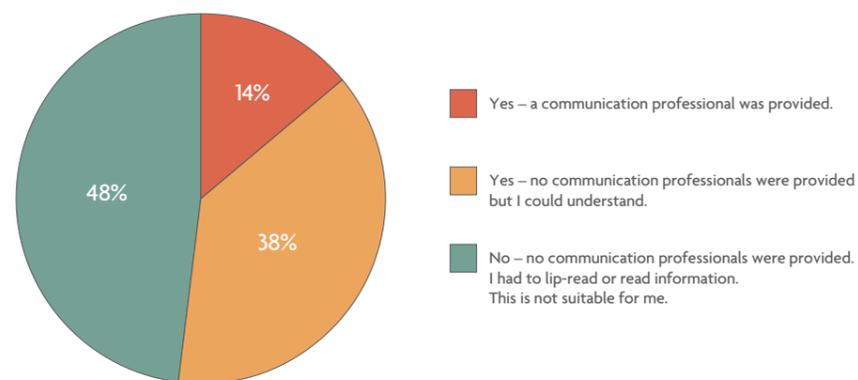
Comments from women about their experience of maternity services were decidedly mixed. Becoming a new mum is, for most women, very exciting - but it is also a time of great emotional and physical change. Our survey revealed that a lack of information and support leaves many D/deaf women feeling unprepared and isolated.

While for those women who received adequate support, pregnancy and birth were positive experiences, the majority of those we spoke to did encounter substantial difficulties when accessing maternity services. Many women were unable to attend antenatal classes, which can provide a valuable social network for new mothers, as well as advice and information, because of a lack of communication support.

during the birth of their baby. Worryingly, some women said that interventions were performed without gaining their full consent, an experience that has been reported in previous research.²⁴

Abortion is a taboo and stigmatised subject, which may prevent some women being able to discuss it with their friends or family. Furthermore, inaccurate and misleading advice is, unfortunately, far too common online, which is particularly worrying for D/deaf women who may disproportionately rely on the internet for medical advice. It is therefore incredibly important that D/deaf women are able to get the information and advice they need about abortion from qualified and impartial healthcare professionals, and that it is presented in an accessible format.

During pregnancy, did you feel you understood all the information at medical appointments?



A recent qualitative study with a group of D/deaf mothers found that they received less information and had less social interaction with other new mothers, and felt anxious about being judged by health professionals about their parenting skills.²³

There is sadly a lack of wider research around D/deaf women and abortion. 1 in 3 women will have an abortion in her lifetime, and it is an area of healthcare many D/deaf women will need to access at one point in their lives.²⁵ It is important that more is done to understand their experience of abortion care.

A lack of communication support was also highlighted with regards to appointments with midwives and during labour, leaving some feeling unprepared for or not in control

Of those women we surveyed who have had an abortion, 30% said a communication professional was not provided during the appointments and they did not understand the information provided. This mirrors Action on Hearing Loss findings that over one-third of D/deaf people feel they may have missed important information when visiting their GP.²⁶



“After daughter born [we stayed in] hospital for one week with no interpreter. Horrible experience.”



“Struggled to get used to the different voices every time I went for an ante-natal appointment.”



²³ Sporek, P. (2014), The Deaf Nest Project.
²⁴ Parsons, 'Deafness, Pregnancy and Sexual Health', and Sporek, The Deaf Nest Project.
²⁵ Stone N, Ingham R. (2011), 'Who presents more than once? Repeat abortion among women in Britain', Journal of Family Planning and Reproductive Health Care Vol. 37.
²⁶ Ringham, L. (2011), Access all areas? A Report into the Experiences of People with Hearing Loss when Accessing Healthcare.