THE DEAF NEST PROJECT

A report into deaf and hard of hearing people’s experiences of maternity care
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A report into deaf and hard of hearing people's experiences of maternity care |
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‘A woman’s relationship with her maternity providers is vitally important. Not only are these encounters the vehicle for essential lifesaving health services, but women’s experiences with caregivers can empower and comfort or inflict lasting damage and emotional trauma. Either way, women’s memories of their childbearing experiences stay with them for a lifetime and are often shared with other women, contributing to a climate of confidence or doubt around childbirth.’

White Ribbon Alliance, Respectful Maternity care, 2011

The Deaf Nest Project is a vision of maternity services where every deaf parent has full access to services, an excellent childbirth and pregnancy experience and the information to make informed choices. The Deaf Nest project aims to improve deaf users’ personal experience, equality of access, choice and control over maternity care. Pregnancy and motherhood are major life events for all women, not least for deaf women. Nevertheless, they need to be accepted and supported in their choice to become parents and to be cared for and treated like every other woman.

The Deaf Nest Project has maximised its engagement through conference, Deaf service users consultation groups, newsletters, deafnest.com website and through extensive use of social media. The Deaf Nest Project has been recognised and awarded the Royal College of Midwives Award, the Slimming Award for Public Health, the British Journal of Midwifery Award and the Iolanthe Trust, the Ann Stewart Award. Moreover, it has been commended by the Cavell Nurses’ Trust and most recently by the Enei, in the Community Impact Award category.

The Deaf Nest believes that understanding, respecting and embedding diversity in maternity care has the potential to make a real difference to deaf women’s experience of pregnancy and childbirth. The deaf world in relation to pregnancy is little known, and there is no one to promote and protect its values and views except deaf people themselves. Additionally, deaf women and hearing impaired mothers are a very small minority among the many thousands of hearing mothers that midwives see every day. Despite that, demand is no less urgent because it is not widespread- after all each mother is an individual and midwives must adopt their care accordingly.

Paulina Ewa Sporek
Founder of the Deaf Nest Project
ACKNOWLEDGMENT

I primarily thank all the deaf parents who took part in this project, without you there would be no project—thank you for sharing your experiences; it was an honour and privilege to hear your emotional stories.

Thank you to the Deaf Health Champions and the SignHealth for all your support, encouragement and commitment to me and the project. Mr Jonathan Swift, your guidance, particularly in those early tentative days and your faith in my ability to undertake a project like this increased my motivation and my self-esteem. Special thanks go to Dr Jacque Gerrard who provided me with valuable feedback on the project and for insight, support and inspiration. Thanks, also, to one of our Deaf Nest Ambassador Dionnie Thomas for her BSL translations and interpreting services. Thank you all.

There are many who have encouraged and supported me with undertaking this project including my midwifery lecturers and midwifery students colleagues and I will continue to be grateful and appreciative of them. There are, though, some who need to be mentioned for their particular assistance with the project. I am particularly grateful to Dr Lesley Choucri, Prof Caroline Hollins Martin and my fellow student midwife Rachel MacPherson.

For the beautiful photographs used in this report I would like to thank Katarzyna Bens (p8, p12, p21, p22, p25, p26, p27, p31, p32, p33, p34, p35, p38, p40, p43, p44, p45, p49, p53, p54, p57) and Amanda Glaspell (p14, p15, p42).

Along with all those mentioned above I must also acknowledge my partner whose support and loving nature are invaluable.

Thank you.
Improving childbirth and pregnancy experience for a deaf couple.

The birth of a child is a momentous and happy occasion in the lives of most parents. Parents expect not only a joyous addition to the family, but also the continuation of the family lineage. Unlike expectant parents with disabilities, expectant deaf parents, like those in any other language minority, commonly hope to have children just like themselves, with whom they can share their language, culture and unique experiences.

Deaf parents face considerable obstacles in their journey of parenthood. They are frequently educated below their capacity, employed below their capability, and viewed negatively by the hearing world because they are deaf. The fact that being deaf is viewed negatively in our society creates complicated interactions between deaf parents and the hearing professionals with whom they come in contact.

Deaf women need to be accepted and supported in their choice to become parents and to be cared for and treated like every other woman.
INTRODUCTION

‘As a deaf boy, the artist struggled to understand the connection between words and images. His discovery of language came when he grasped that the fingerspelled word “B- A-L-L” matched the picture of a ball, and the door of enlightenment opened for him. Before, his mind was a desert. After, his vision was transformed by primary colors- red, blue, yellow- which were to change his life. The flower in full bloom is William’s rendering of the moment of discovery: “I understand!”’

L.K.Elion

My Eyes are My Ears

Homage to Harry R. Williams

Hearing loss is a major and growing public health issue, currently affecting more than 10 million people in the United Kingdom (Action on Hearing Loss, 2011). Additionally, the World Health Organisation (WHO) (1997) predicts that by 2030 adult onset hearing loss will be in the top 10 disease burdens in the UK, above cataract and diabetes. It has significant personal (Royal National Institute for the Deaf, 2011) and social costs (Shield, 2006). What evidence is available indicate poorer physical health among deaf people (Sign Health, 2008). Kochin and Rogin (2000) study shows strong correlation between hearing loss and physical, emotional, mental and social wellbeing. Furthermore, Young (1990) and Oliver (2004) argue that issues such as, anxiety, depression, isolation and lessened self-esteem constitute a form of ‘social oppression’ or ‘social death’, rather than being ‘just’ quality of life issues.

The Action in Hearing Loss report (2011) shows that hearing loss is under-researched, unrecognised as a public health issue, and people with hearing loss have significant unmet clinical and social needs. There is also a failure in wider society to respond to the communication needs of people with hearing loss. Sign Health’s report Why do you keep missing me? (2008) shows that 32 per cent of deaf people find it difficult to explain their health concerns and 35 per cent leave an appointment not having understood what they have been told. Moreover, most recent research form Sign Health (2014) shows 70% of deaf people who hadn’t been to their GP recently had wanted to go, but didn’t, mainly because there was no interpreter. It is shocking and unacceptable to realise that deaf parents are deprived of fundamental human rights, and yet it is true.

Deafness is unique in that it crosses barriers of age, gender, economic status and ethnicity (Fusick, 2008). It is particularly complex in the context of the ‘disabled/abled binary’ (Skelton & Valentine, 2003). Generalisation is unhelpful since impairment is individualised and manifests itself in emotional, psychological, social, and physical dimensions of a person’s life (RCN, 2007). The psycho-emotional barriers deaf women and their families encounter include discriminatory health and social support services (Oliver, 2009), and limited access to information (Munoz-Baell & Ruiz, 2000). Those social barriers not only erect restrictions to participation in the normal life of the community (Marks, 1999), but also place limits on women’s psycho-emotional wellbeing. For instance, feeling worthless, of lesser value, stressed or insecure (Thomas, 1999).

Communication is the most serious barrier for people with hearing loss. It plays a central role in underpinning informed consent and informed choice. In order to make informed choices, a woman needs accurate and accessible information (RCM, 2008). Iqbal (2004) recognised that deaf parents are unable to access information and this is mainly due to staff inability to communicate in sign language or because of a lack of deaf awareness. Elaborating this theme, Price (2012) utilises the idea that any communication barriers may compromise the quality of care. Other have followed a similar path when thinking about the importance of obtaining informed consent (NMC, 2008) and ensure deaf women’s rights and expectations are met under the Patient’s Charter and Disability Discrimination Act (1995) (Scullion, 1999).
For example, in his deliberations on the specific social needs of deaf women, Atkin et al. (2002), state that deafness presents additional barriers such as being socially and morally more vulnerable. Deafness may undermined women’s confidence and make it difficult to sustain a positive self-image (Atkin et al., 2002). The most recent ‘Saving Mother’s Lives’ report (CMACE, 2011) has again identified the links between social exclusion and vulnerability and adverse pregnancy outcomes.

Additionally, there are huge barriers to access health services and lack of integration between them. British Sign Language (BSL) interpreter is not always available to attend every antenatal, intrapartum and postnatal appointment. The presence of the interpreter is crucial to interpret findings, communicate any concerns couple may have and most of all to ensure informed choice is provided. ‘Midwives can learn sign language’ (Kelsall et al., 1992). This is not to replace the interpreter but to enable the basic communication when the interpreter is not present.

Childbirth can be an empowering and embracing life experience for a woman and her family. For this to be a positive and fulfilling experience, midwives and other healthcare professionals need to be empowered and enabled to deliver care that is woman-centred to meet individual needs, at the same time as being evidence-based. ‘Embracing diversity is key to change’ (Rotheram, 2007).

‘Deaf Nest’ project will attempt to produce good practice guidances, to seek ways to remove barriers and to explore ways to make adjustments that are both creative and flexible to meet the needs of a deaf couple.
EXECUTIVE SUMMARY

Objectives

The Deaf Nest project aims to implement clear pathways to seek ways to remove barriers and to explore ways to make adjustments that are both innovative and flexible to meet the needs of deaf families.

Goals

The project includes components designed to ensure dignity and address deaf couples’ needs in the journey of childbirth. One important component is the consultation group for deaf parents to make sure that the voice of deaf women and their families is heard. Integral to this is promoting deaf awareness for midwives by organising regular workshops, service users days and conferences. The main purpose of the midwife role in the project is to bring evidence-based, expertise knowledge to the program. Finally, project seeks to work in a collaboration with Software Engineering Department at the University of Salford to design a new software to transfer sound of fetal heartbeat to vision and vibrations.

Solution

The implementation of clear guidances, early assessment form, effective referral, deafness awareness study days and ‘Deaf Nest’ support packs will result in an improved deaf access to information, ongoing assessment of need, improved health and lifestyle choices and greater family involvement. The project is very cost effective and can be easy replicated across the UK as all resources will be made available for free on the website. By the end of 2014, this project aims to have gathered a wide range of learning innovations and resources that can be spread out more widely to improve quality of maternity care for deaf people.

Moreover, the project aims to improving deaf access to information by producing visual aids, leaflets, flash cards and videos for antenatal, intrapartum and postnatal education. These will contain basic up-to-date information specific to each stage of pregnancy, presented in British Sign Language. The deafnest.com website was created where all relevant information will be available for free for deaf people as well as health professionals.

The first ‘Deaf Nest’ conference was held on the 11th of June 2014 at the University of Salford.
Hearing loss is a major public health issue affecting over **10 million** people in the UK – one in six of the population.

It is estimated that by 2031, 14.5 million people in the UK will have hearing loss. This is a potential public health crisis, yet has been ignored. Hearing loss has high personal and social costs, and it is an expensive and neglected topic. Hearing loss is a public health issue and people experiencing hearing loss have significant clinical and social needs. There is a failure in wider society to respond to communication needs of people with hearing loss. £1.34 million has been spent on research about hearing loss compared to £49.71 million spent on research on cardiovascular conditions for every person affected.

![Chart showing research funding](chart.png)

Hearing loss has significant personal and social costs. The barriers deaf families encounter include discriminatory health and social support services and limited access to information. Those barriers not only erect restrictions to participation in the normal life of the community, but also place limits on women’s psycho-emotional wellbeing. This being a significant draw back to the research since the ‘Saving Mother’s Lives’ report (CMACE, 2011) has again identified the links between social exclusion and vulnerability and adverse pregnancy outcomes.

(Action in Hearing Loss, 2011)
‘How the health service is failing deaf people’ - The world’s first large study of Deaf health produced by the Deaf Health Charity SignHealth.

In their research deaf people reported feeling excluded, marginalised and disenfranchised by the healthcare system. They face constant barriers as they try to take control of their own health. Modern healthcare relies on people being given information and then making healthy choices, but deaf people are just not being given the information they need. Health information from the NHS and others should be routinely translated into sign language, to give deaf people the same access to information as everyone else.

This research reveals a story of unintentional neglect, shortened lives and wasted money.

Generally speaking, Deaf people are as active as hearing people, eat a similar amount of vegetables, drink less alcohol and smoke far fewer cigarettes. So, why are they more likely to be overweight, twice as likely to have high blood pressure, and four times as likely to be on the verge of diabetes? Why are so many unknowingly living with health issues which can lead to heart attacks, strokes and other serious conditions? The answer is lack of information, poor communication, and unnecessary difficulties in getting to the doctor in the first place. All of that is outside the control of Deaf people themselves.

(SignHealth, 2014)
The ramifications for the NHS of a failure to provide adequate communication support to those who need it are serious.

This report reveals that, despite the frequency with which deaf and hard of hearing people use the National Health Service (NHS), the level of service they receive, in both GP surgeries and hospitals, often falls short of what they could reasonably expect. The research took place in the context of the Disability Discrimination Act 1995 (DDA) placing a legal obligation on the NHS to make reasonable adjustments to accommodate disabled people’s needs.

35% of deaf and hard of hearing people had experienced difficulty communicating with their GP or nurse and 32% found it difficult to explain their health problems to their GP.

77% of BSL users who had visited hospital could not easily communicate with NHS staff. The proportion who had experienced difficulty was the same for both emergency. The evidence demonstrates a disturbing picture where people who rely on BSL for their communication needs are not being supported and must overcome difficult and often distressing obstacles in order to access the NHS.

‘Many people are ignorant as to how to speak to a deaf person. Recently a consultant could only shout [at me] when all that was needed was to speak slowly and clearly.’

This report demonstrates that there are currently serious problems in the delivery of services to deaf and hard of hearing people and that action is needed to address those shortcomings. The NHS needs to work towards meeting existing and forthcoming obligations to its deaf and hard of hearing patients.
‘No sign of support’- The study of understanding young people’s sexual and reproductive health needs produced by the British Pregnancy Advisory Service and the Deafax.

One third (34%) of the women we surveyed had been pregnant. 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 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. 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.

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 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. 48% of women said a communication professional was not provided and they did not understand the information provided.

During pregnancy, did you feel you understood all the information at medical
For this was the first time that data has been collected nationally by the NHS which recorded whether a patient was deaf. The significance of this cannot be overestimated.

This report was publish in a response to the 2009 GP Patient Survey. The GP Patient Survey was answered by nearly 2 million people in England. The results show that Deaf people are less happy with certain aspects of primary care. Deaf people are also significantly less healthy than hearing peers. These are the two crucial conclusions from looking at the data. Staff throughout the NHS should review their practice to see whether improvements can be made for deaf people. This will often have a positive effect on patient care generally. If a service is working well for deaf patients then it is probably working well for all patients. Deaf Awareness training for staff will give them an understanding of the care pathway the patient’s journey through the system] and demonstrate the barriers deaf people face. The GP Patient Survey results confirm what has been suspected for a long time. Deaf people are less satisfied with access to primary care, and are probably less healthy as well. The lack of reliable and useful data up until now is surprising but the survey results. What is now clear is that primary care services need to change. Not in any dramatic way but one which brings about a change in attitude, which in turn brings about improvements to deaf peoples’ health experience. Changes of this kind would not be costly and indeed, the long term would see some significant cost savings. More importantly, deaf people would be able to access health services on an equal footing with hearing patients. They would no longer feel and be treated like second-class citizens.

(SignHealth, 2008)
Parents have been left frightened by limited information, no communication provision and a general lack of understanding about the culture of Deaf people.

In June 2013 the Deaf Nest Project in a partnership of the Deaf Health Champions and the Manchester Deaf Centre set up the consultation group for deaf parents to make sure that their voice is heard. This involved communicating and listening to deaf parents experience of pregnancy and childbirth and involving them to bring about change.

Information was also gathered on local and national charities, drawing from websites, email correspondence and face-to-face meetings. There are few local charities across the country which offer support and practical help to deaf people. The author met with two national charities- the Sign Health and the Deaf Health Champions. Both these organisations have strong working relationship with the UK Council on Deafness and a history of collaborative working. While both of these organisations are working towards improving access to healthcare and information about health and wellbeing, there is lack of information and services specific to pregnancy and childbirth.
In a collaborative work by Dr Joanna Downes, parenting project manager at Action Deafness Leicester, and Bernadette Gregory, senior lecturer in midwifery at De Montfort University, 9 in depth research interviews have been undertaken with mothers. Some have been deaf from birth, others have become deafened; some lip speak, some wear hearing aids and/or use a Minicom system, others who use BSL and/or use a cochlear implant and oral speech. This qualitative approach where participants are able to discuss real life scenarios affecting them as individuals is in line with the adoption of the social model of disability research methodology advocated by many writers on disability issues over many years.

The researches found that women received less information regarding parenting issues and they had less social interaction with other mothers. Moreover, it was difficult for mothers to access hospital or midwife for help unless mobile number was given. Other issues included fear and anxiety of being judged by health professionals regarding caring for a baby skills.

Additionally, there is little literature available on providing maternity care to deaf parents. The lack of relevant literature suggest that deafness and pregnancy are two concepts rarely considered together. Despite the most recently available statistic which shows a dramatic increase in hearing loss, little has been said or done in relation to pregnancy and childbirth. The pregnancy book available for deaf parents costs of £14.99 but hearing pregnant women are given one for free- only one example of inequality in care provision. Consequently, there is an acute need to train midwives and other medical staff in deaf awareness and associated communication skills. In fact, midwives need to integrate the model of care with the vision represented by the six Cs of care, compassion, competence, communication, courage and commitment.

As with all areas of Health & Social Care, it is much evidenced through the project that antenatal and postnatal services are frequently failing to meet the basic needs of deaf mothers and fathers that relate to to their unique communication, linguistic and cultural needs.
KEY FINDINGS

The use of social media is a popular mechanism for support

There is a magnificent shift in the way people access their services. This is specially true in relation to Deaf community who has limited access to information and services. The Deaf Nest Project recognised that social networks offer a great opportunity to engage with service users and provide Deaf parents with information they need to make informed choices about their pregnancy and childbirth.

Lack of comprehensive data and statistic which impacts on service planning

There is little literature available on providing maternity care to Deaf parents. The latest statistic of how many Deaf women were accessing maternity care has been done more than twenty years ago.

Collaborative working between national and local charities is evident and offers an opportunity to move forwards

‘Deaf Nest’ project recognise that engaging with other organisations increases the capacity for development, and strong management and leadership are essential to fully utilise the participation of volunteers and drive the project forward. Therefore, the project is initially delivered in partnership with Manchester Deaf Centre, Deaf Health Champions and SignHealth whose aim is to ‘improve personal experience, equality of access, choice and control over health care for deaf people’. Additionally, it was agreed support from partner agencies including: Deaf Parents UK, Genie Network, Merseyside Society for Deaf People, Deaf Vision Cumbria and University of Salford to ensure quality and effectiveness of program.
The availability of an interpreter, particularly in labour, varies between and within regions

The presence of the interpreter is crucial to interpret findings, communicate any concerns a couple may have and most of all to ensure informed choice and confidentiality. An urgent review of interpreter booking system is needed along with wider use of technology.

But we don’t see many Deaf mothers, do we?

Deaf women and hearing impaired mothers are a very small minority among the many thousands of hearing mothers that midwives see every day. Therefore, many midwives do not have the opportunity to regularly practice their skills in using sensitive communication and support. Despite that, demand is no less urgent because it is not widespread- after all each mother is an individual and midwives must adopt their care accordingly.

No forward planning and liaison between agencies

The careful thought should be given to working in a partnership with other professionals and voluntary organisations. Joined-up care through the antenatal, intrapartum and postnatal periods by an integrated multi-disciplinary team is particularly important in order to provide midwifery care tailored to the individual needs. It appears that many health professionals are not aware of the charities and organisations who offer support to Deaf and hard of hearing people.

Deaf mothers are receiving less information regarding pregnancy and parenting issues

It’s a fact- there is no accessible resources about pregnancy and parenting out there. The pregnancy book available cost of £14.99 for Deaf parents (not available in the UK anymore), but is given free to other pregnant women, and is an example of inequality in care provision. There is an acute need to train midwives and other medical staff in Deaf awareness and associated communication skills. Classes in basic Sign language and better teaching aids and video material should be available both for midwives and hearing impaired parents.

Difficulties with accessing hospital and midwife

There is clear dissatisfaction amongst deaf patients in relation to telephone access. Some deaf people will use a textphone (minicom) or fax, but increasingly SMS (text messaging on a mobile) or e-mail will be preferable. The key action is for the practice staff to discuss the means of communication with the patient to see what will work best for them. The RNID’s report A Simple Cure (2004) provided data which suggested that 24% of deaf people had missed appointments because of poor communication, such as being ‘called’ when it was their turn. A shocking 19% had missed more than five appointments because of communication difficulties.
CASE STUDY- LAURA

Since finding out I am expecting a baby, I have come across so many more barriers.

Laura is 29 years old first time mum-to-be and profoundly deaf. She has been deaf since she was three years old and rely on lip reading. She has worked as a press officer for the government and is freelance journalist. Most recently she is working in marketing for a charity (RNIB) in London. She is passionate about trying to improve services and access for deaf people especially for deaf parents to be. She is sharing with us her experiences of becoming a deaf parent for the first time and is campaigning for better accessibility for deaf people.

Is stressful knowing that there is no additional services put in place for us deaf parents to be.

Since finding out I am expecting a baby, I have come across so many more barriers. Deaf parents to be do not really have easy access to antenatal information. I can’t even book antenatal classes myself. I have to get my fiancé to do it. Also, I can’t even call up to find out about things that I am entitled to like Child Benefit. Again, I have to rely on my fiancé. I have personally asked my midwife if I can have her mobile number to be able to text her about results; when you are pregnant you need to have blood tests regularly and I argued why should I have to get my fiancé to call up for results and that it would be better if I could text for the results. Luckily I have an understanding midwife who takes her time to text me.
I have missed an appointment due to not hearing my name being called out.

I had antenatal appointment in the hospital and had to go by myself as my fiancé couldn’t get the time off work. I sometimes hate going to hospital appointments by myself as I have to constantly try and listen out for my name being called and concentrate on what the doctor is telling me. I sometimes think my eyes deceive me when I am trying to lip read and think is that me they are calling out or is it another Laura?! Sometimes I get up at the wrong time and it is someone else they are calling out. I wish hospitals had a number system rather than calling out your name, I have fed this back to the NHS trust before as I have missed an appointment due to not hearing my name being called out. I also suggested it would be easier if I could have sms or email access for appointments as why should I rely on my fiancé to make all the calls especially for my antenatal classes?

I do feel frustrated that deaf parents are not given accessible information.

We have been given a lot of literature for things like breast feeding support groups, children’s Sure Start centres, information on classes you can attend with your baby like baby massage groups and a telephone support group where you can share your concerns and chat about your worries about anything baby-related. But there is one downside it’s all telephone only! I asked if there was an email service or text service, but got the obvious response: ‘we don’t have that service.’

After having Poppy I was on the ward and my buzzer didn’t work and I was told that the midwives were aware of my hearing loss as I was worried I wouldn’t be able to hear my baby cry at night. But they didn’t let me know when she was crying I just simply didn’t sleep for 24 hours!! I feel stressed and anxious because I wanted to be home with my partner who could help me out. Being home with Poppy is relaxed but I do feel isolated at times, for example I can’t call up the doctors if there’s anything wrong with Poppy, I have to text my partner when he’s at work to call up on my behalf. Then again they say they need more information and my partner is not with me as he’s at work. I can’t call up local children’s centre to find out what programmes they have on for babies and again I’m missing out. I do feel frustrated that deaf parents are not given accessible information.

I would like to think that I have a support network around me available like hearing people have.

The Deaf Nest Project highlights that deaf parents are getting left behind when it comes to maternity services. It is true. I have seen this firsthand and it is stressful knowing that there is no additional services put in place for us deaf parents-to-be and parents. I would like to think that I have a support network around me available like hearing people have for things like breast feeding groups.
There are approximately 625,000 more appointments made by deaf people that would be expected in a hearing population.

Missed appointments for deaf and hard of hearing people costs the health service £20m every year.

Similarly, in 2004, A Simple Cure estimated that missed appointments for deaf and hard of hearing patient cost the health service £20m every year and that was due to poor communication, such as being 'called' when it was their turn.
Maternity and deafness: a complex web of interrelated factors.

The key principle here is an understanding of interrelated factors experienced by D/deaf women and their families when accessing maternity services. It is vital for the midwife to consider these factors and work towards improving the standard of care provided to D/deaf couples on their journey to parenthood. This is achieved by an early assessment of the woman’s needs, wishes and aspirations.
Primary Objectives

- Overcome prejudice and barriers by increasing public awareness and offering equal choices to services users.

- Promote deaf awareness for midwives and other health professionals by organising regular workshops, service users days and conferences. This will enable engaging and building trusting relationship with deaf women.

- Explain how midwives can learn sign language and be innovative by using adaptive and creative approaches to meet individual needs of deaf women.

- Describe an effective provision of help to deaf mothers and their families by focusing firmly on the experience of the woman’s journey through childbirth and transition to the motherhood. Provide accessible and accurate up-to-date information in accessible format to enable informed choice.

- Identify and assess needs and support needed by effective referral, and development of good practice guidelines, information leaflets and practical suggestions.

- Strengthening an effective provision of care to deaf couple by promoting culture of inter-professional collaborative practice.

- Comply with the Equality Act (2010).
The real work to implement the Deaf Nest Project objectives relies on individuals acting to embed its values.

A great deal of support and enthusiasm is building around the Deaf Nest Project, with a strong collaboration being demonstrated by supporting national and local charities, midwives and other health professionals. The evidence of this enthusiasm and commitment has been demonstrated during the past twelve months, reaching its momentum at the first Deaf Nest Conference held on 11th of June at the University of Salford.

Making appropriate changes in care provision can ensure that Deaf mothers will be happier with the care they receive. In order to offer greater choice and control for deaf women and include them in provision of care, midwives and other health professionals need to understand the health inequalities they experience to access healthcare services.

My pledge is to work with midwives and other health professionals across England to help them to understand deaf Women’s needs and problems they may face when accessing maternity services. And to work with deaf parents to provide them with best start in parenthood.
6 CS: AN APPROACH FOR DEAF PARENTS

**Compassion**
Awareness among midwives about caring for women with unseen disabilities, such as deafness and be aware of the impact impairment may have on their life. Taking a positive approach to the pregnancy of a deaf woman where emotional support is as important as practical support.

**Communication**
Providing accessible, up-to-date and evidence based information enabling deaf parents to make informed decisions. Making full use of technological solutions to improve deaf access to information and services and correct use of interprets.

**Competence**
Supporting midwives and other health professionals to gain knowledge and skills in deaf awareness which influence positive pregnancy and childbirth experience and the best start in life for babies.

**Courage**
Adopting a position of ‘determined advocacy’ for women’s civil rights under protective laws such as the Disability Discrimination Act (1995) and the Equality Act (2010), and be prepared to assume non-traditional roles.

**Commitment**
Developing and delivering high quality maternity services which meet communication and cultural needs of deaf women and their families.

**CARE**
A maternity services where every deaf parent has full access to services, an excellent childbirth and pregnancy experience and the information to make informed choices.
The Deaf Nest Project is starting its journey with working in partnership with deaf women and their families to achieve a positive childbirth and pregnancy experience. Actively engage with service users by organising consultation groups to inform future maternity care provision. Finally, the Deaf Nest Project is working in partnership with voluntary sector and other deaf organisations to ensure personalised maternity care and enhanced care pathways.

First stop is ensuring educational and developmental opportunities to support midwives in practice. These include deaf awareness workshops and conferences. Making use of technological solutions and making all materials available for free on the deafnest.com website.

Next stop is benchmarking the Deaf Nest Project performance through feedback from deaf parents, midwives and other maternity workers.

The final destination is maternity service where every deaf parent has full access to services, an excellent pregnancy and childbirth experience and the information to make informed choices.
NATIONAL ACTIONS

Action can be taken at all levels of the health service. Little changes will make a big difference.

- Developing policy and programmes for the public health role of midwife in providing care to deaf parents.
- The Deaf Nest Champions and the Deaf Nest Ambassadors challenge. A BSL Signer/Interpreter in every NHS maternity service.
- Actively engaging across voluntary sectors by integrating resources of local and national charities.
- Developing accessible evidence based on NICE guidance and putting it into practice.
- Provide feedback from deaf parents to build on a rich picture of the Deaf Nest Project in action. CQC specific questions incorporated into the national maternity survey.
- Use feedback and action plans coming out of feedback to improve the experiences of deaf parents.
- Publish information and statistics obtained from local and national events and the Understanding Deafness Evaluation Tool (UDET).
- Developing the Deaf Nest Toolkit for midwives and other maternity workers.
- Providing training and information for midwives and other maternity care workers.
- Providing training and support to student midwives and implementing deaf awareness module in midwifery curriculum.
- An enhanced maternity care pathways for deaf parents in order to improve their experiences of maternity care.
- Working in partnership with deaf parents to achieve a positive transition to parenthood. Deaf parents invited on to Maternity Service Liaison committees and clinical networks.
Deaf parents have to be able to access maternity services on an equal footing with hearing parents. This is not negotiable.

- Support midwives and maternity workers to maximise their contribution to the Deaf Nest Project
- Publish and discuss local outcomes from workshops for deaf community and maternity workers.
- Enable midwives and maternity workers to gain knowledge of deaf awareness and basic health signs and skills to provide care more effectively to deaf parents and their families.
- Strategies to secure staff engagement through annual conferences, service users days, workshops, fundraising and deaf awareness days.
- Implement the Deaf Nest Awareness Test.
- Commissioners to ensure locally agreed strategies to deliver high quality maternity care to deaf parents and their families.
CALL TO ACTIONS

NHS need to make reasonable adjustments to ensure their services are fully accessible to deaf and hard of hearing parents and their families. We need to see urgent action taken to improve the delivery of maternity services.

- Develop skills as the Deaf Nest Champions making every deaf parent count. A Deaf Nest Champion (midwife or midwives) in every NHSTT.
- Actively listen to, seek out and act on deaf parents and maternity workers feedback identifying issues and ensuring that deaf parents and midwives voice is heard.
- Local commissioners to support midwives and maternity workers in their efforts to improve maternity care to deaf parents and their families.
- An updated NHS Disability Access Audit which includes the needs of deaf and hard of hearing parents.
- Ensure deaf awareness and basic sign language training for ‘front-line’ maternity staff and implement simple measures to ensure that communication needs are met. Ensure that all maternity units have at least one ‘front-line’ member of staff who has been formally trained in deaf awareness.
We need people who are friends and supporters of the Deaf Nest project, and who can be the face of the project their communities across the England.

Ambassadors are passionate volunteers and influential supporters, across a wide range of industries and regional areas that help forge fundraising relationships and raise awareness of deafness awareness. They use their professional skills to assist the project, create opportunities for the project to raise money or profile, represent the project in the media when asked and attend events and encourages others to do so.

Ambassadors will champion the cause and often challenge opinions and perspectives whilst demonstrating loyalty and commitment to the project’s vision and values.

Ambassadors do vital work for the Deaf Nest project, including:

• Sharing information with friends, family or co-workers
• Making introductions to contacts who may support the Deaf Nest project
• Inspiring others to sponsor the Deaf Nest project
• Participating in and promote campaigns throughout the year
• Representing the Deaf Nest project at events
• Positively promoting the Deaf Nest project through local and social media.

If this is you and you are looking for an exciting role within the voluntary sector, please see contact page for contact details.
As soon as I heard about the Deaf Nest Project I knew I had to get involved.

Dionne Thomas works as a professional BSL / English interpreters and has worked within the Deaf community for over 14 years. As well as being involved with several Deaf-led organisations, she also runs a translation service providing Deaf BSL users with access to written English through British Sign Language videos. Dionne currently lives in Lancashire after spending 8 years studying the British Sign language, interpreting and translation at the University of Central Lancashire. She now holds a Post Graduate Diploma in BSL / English interpreting & translation.

This is an amazing project and with funding could solve many of the current issues facing deaf mums and their families.

As soon as I heard about the Deaf Nest Project I knew I had to get involved. As an interpreter working in medical settings I knew that pregnancy and childbirth information was sadly overlooked for Deaf mums and the Deaf Nest Project seemed like the perfect solution. After initially enquiring about volunteering it became clear that Paulina and I had the same passions. I was soon asked to be the official ambassador. My role has been to promote the project, source support both practical and all kind. I have also poured many hours into the sign language translations for the deafnest.com website and the first Deaf Nest conference which I have thoroughly enjoyed. This is an amazing project and with funding could solve many of the current issues facing deaf mums and their families. I will continue to support Paulina and the Deaf Nest in any way I can as this is an important issue close to my heart.
I am delighted and honoured to be a Deaf Nest ambassador.

I am delighted and honoured to be a Deaf Nest ambassador. I first met Paulina and heard of the project in 2013 at the Royal College of Midwives Annual Awards judging event. I was astonished at the work that Paulina had embarked on whilst studying and carrying out her clinical midwifery duties as a student midwife. I learned about the impact of hearing loss on deaf parents and that babies born with deafness is a major public health concern which affects around 10 million people in the UK. Within the space of half an hour and listening to Paulina’s presentation, I was immersed in the world of deafness. I learned how this impacts on deaf pregnant women and the challenges and barriers that they have to overcome to access maternity and midwifery care.

I realised the size of the problem and how important this issue is for deaf women and the impact on health outcomes for babies born to deaf parents.

I suddenly realised the size of the problem and how important this PH issue is for deaf women in the UK and the impact on health outcomes for babies born to deaf parents. I have been in the midwifery profession for over thirty years not knowing nor understanding that women with hearing and deaf issues have had so many challenges accessing maternity care. I have since taken a huge professional interest in the work that Deaf Nest is doing. As an ambassador, I will make every effort to promote and support the award winning the Deaf Nest project as I am keen to help Paulina in her quest to bring this to the attention of commissioners and healthcare providers. By improving access for deaf women, perhaps health outcomes and health benefits will be realised and services for pregnant and deaf women will eventually be integrated into main stream maternity service.
Want to do your bit but not sure where to start? Your time is one of the most valuable gifts you can give.

People choose to volunteer for a variety of reasons. For some it offers the chance to give something back to the community or make a difference to the people around them. For others it provides an opportunity to develop new skills or build on existing experience and knowledge. Regardless of the motivation, what unites them all is that they find it both challenging and rewarding. We want to ensure deaf awareness and basic sign language training for ‘front-line’ maternity staff and implement simple measures to ensure that communication needs are met. To achieve that we call midwives and maternity workers to become the Deaf Nest Champions. So, we can ensure that all maternity units have at least one ‘front-line’ member of staff who has been formally trained in deaf awareness.
The National Breastfeeding Helpline offers web chat, a different channel of support, especially suitable for people with hearing or speech impairments.

The Deaf Nest project is working in a collaboration with the National Breastfeeding Helpline by referring deaf parents should they have any questions related to breastfeeding. The National Helpline offering breastfeeding support and information for mums, and for those supporting them- dads, grandparents, friends and health professionals.

The telephone helpline is open from 09:30 am to 09:30 pm every single day of the year. All calls are answered by highly trained volunteers- all are mums who have breastfed- offering mother centred, non-judgmental, confidential and evidence based information.

The National Breastfeeding Helpline offers web chat, a different channel of support, especially suitable for people with hearing or speech impairments. The web chat offers confidential, online, instant messaging support service that works on a laptop, tablet or mobile, and provides exactly the same level of support as you would receive on the telephone.

The web chat has been launched on April 2014 as a pilot project, used social media to invite mums with hearing impairments to get involved with the trial period. Nearly 200 chat requests so far. Around 40% of these have been answered immediately. The National Breastfeeding Helpline is in the process of training more volunteers and hope to scale up the project for World Breastfeeding Week in August.

To use Web Chat visit:
www.nationalbreastfeedinghelpline.or.uk
June 11, 2014  The vibrant programme offered a range of attractions including fabulous speakers and presentations, workshops, art displays, raffle tickets, interactive activities, service users personal accounts, Deaf Nest documentary and more, allowing the opportunity to reflect on the personal and professional development.
CONFERENCE NUMBERS

9 men

185 women

194 delegates
Jonathan Swift  
*The acting Project Manager for the Deaf Health Champions project*

Jonathan is the acting Project Manager for the Deaf Health Champions project and is based at the Manchester Deaf Centre, where he has been working for 6 years. His current role is to manage the DHC project, which is a Department Of Health pilot project that covers the Greater Manchester, Merseyside & Cumbria regions. His experience of working within the Deaf community, has helped him to gain an understanding of the experiences a Deaf or hard of hearing person may be going through, may it be health, volunteering, employment, education, family, identity or housing. He is proud to work within such a unique community.

Janice Connolly  
*The volunteer co-ordinator for the Deaf Health Champions project*

Janice Connolly is Deaf Health Champions volunteer co-ordinator and is profoundly deaf. She has been an active member of the deaf community since she was in school. She is an experienced British Sign Language tutor. Her role with the Deaf Health Champions project is recruiting deaf members of the community who then receive training and awareness around subjects, such as healthy eating and our recent “walk for health” event. The volunteers learnt how to plan and lead a group of people in walks that will ultimately encourage people to be more active.

Sue Gill  
*Manager of SignHealth’s Constance Way Supported Living CQC Care Home for Deaf People*

Sue Gill is the manager of SignHealth’s supported living care home in Leeds. She has worked here for 16 years, starting as project manager. As the project developed, tenants wanted to move out into the community so she established an outreach service to support tenants moving on, and also people in the community who needed support to remain in their own homes. In 2010 she was approached by Supporting People to set up a Housing support Service for Leeds residents, again providing support to people who needed it to remain in their own homes. She had difficult personal experiences of the maternity services, and then went on to serve on the maternity services committee of the then Community Health Council, and have served on various bodies since the CHC’s were disbanded.
To never hear your child say Mummy is... I can’t describe it. So to sign it—pretty special.

Lesley is a mother to four ladies and a midwife working full time in a large and busy delivery unit at Central Manchester Foundation Trust. In 2005 she was expecting her fourth child. Immediately post-delivery Amélie became evidently unwell and after alerting the midwife, a doctor re-assessed her and transferred Amélie to the neonatal department. A long 5 months initially hospitalised and a further 22 trips to theatre and several lifesaving emergency surgeries on, and she is the very proud parent of Amélie who also happens to have CHARGE syndrome.

And so Lesley’s journey began, from advocacy to speaking up for Amélie’s needs in healthcare and education. As a midwife and mother deaf awareness has become a priority for her and a dual role. Every deaf child will become an adult and may access maternity care too. Lesley endeavour to continue to raise awareness of a paucity of simple sign language in the hospitals. This prompted her NHS pledge for simple sign language to be part of everyday clinical care. To enable Amélie to be fully included in her care because she deserves and wants to be in control as she matures.

‘Her world is silent so she hears nothing. If she’s got a silent world and then nobody signs to her, then it becomes a very lonely, very isolating world. To sign to Amelie brings out the very things about her that are happening to her each day to enable her to make sense of the care. If you don’t sign to her she doesn’t know.’

‘I want to pledge that all health professionals learnt the basic of simple sign language and to continue to raise awareness so that they can communicate to people like Amelie who are deaf.’

Lesley said: ‘The Deaf Nest Project is the start of something special for deaf women. I hope it’s brings about the required communication and support changes required for deaf women to be treated as equals in society.’

The Deaf Nest Project is the start of something special for deaf women. Amongst us in the NHS we could make a positive change. So do it. Take the plunge, do it, make the change.
Being raised by a deaf mum and a hearing father has gifted me with so much and for this I am truly appreciative and grateful.

Vivien Sabel is a Child Of a Deaf Adult (CoDA), the award-winning author of The Blossom Method - The Revolutionary Way To Communicate With Your Baby From Birth and a registered Psychotherapist. She formerly trained as a BSL Interpreter (University of Bristol) and now runs her own international psychotherapy/clinical service for both Deaf and hearing children and adults.

Vivien is a published researcher and her paper ‘Life After Delivery’ was published in the European Journal for Qualitative Research in Psychotherapy. She works with many parents and babies to support them with Postnatal Depression where she utilises both The Blossom Method and her psychotherapy skills to create and support positive change.

The Blossom Method was published in 2012 and it has received international acclaim; most recently Vivien was nominated by Professor McAlpine (University of Sydney) for an award from the World Association for Infant Mental Health. Vivien was commended by world leaders in infant mental health for “her wonderful contributions to the field of communication.”

Vivien teaches psychotherapy and The Blossom Method has been added to the attachment theory curriculum. Her latest writing project for Professor McAlpine, is a chapter on infant communication for her latest volume of Inspired Children: How The Leading Minds of Today Raise Their Kids. Her attunement to infants and their non-verbal expressions sees her being a regular contributor to international conferences, global publications & worldwide media including The Times of India, BBC. Junior and Mother and Baby.

Vivien is a keen advocate for breastfeeding. She has had personal experience of birth trauma and infant loss. In February 2012 she was diagnosed with hearing loss, this she sees as a further gift from her own deaf (non-signing) mother.

The Deaf Nest Project is an incredible opportunity to discover more about what really matters to the deaf community. If you want to be at the cutting edge the Deaf Nest Project is the place to be.
Sarah Powell

*Clinical Psychologist Step 3 Practitioner*

Dr Sarah Powell is profoundly deaf and gained a Doctorate in Clinical Psychology at the University of Liverpool. She is one of only four Deaf Clinical Psychologists in the United Kingdom. Sarah currently holds the post of Clinical Psychologist/Step 3 Practitioner at BSL Healthy Minds (Sign Health), providing Psychological Therapy services for deaf, deafened and deaf/blind individuals experiencing depression and anxiety. Sarah has a long history working and volunteering in different organisations involved in mental health and deafness including John Denmark Unit and Alpha Hospitals. She is passionate about ensuring that psychological therapies are delivered in an accessible way for all deaf people.

**Deaf mothers experience inequality during ante and post natal care.**

Sarah was an active member of the initial Improving Access to Psychological Therapies (IAPT) steering group, set up to explore the needs of the deaf community in this clinical area. The result being, the establishment of BSL Healthy Minds. Sarah is well versed in using Cognitive Behavioural Therapy (CBT) and has adapted a variety of relevant materials. The adapted materials have made therapy more meaningful and accessible for deaf BSL users, including those with post natal depression. Sarah is an Honorary Lecturer at Liverpool John Moores University and continues in her quest to ensure deaf people have equal access to psychological therapies in the community.

**It is important to ensure that deaf parents have equal access to psychological therapies in the community.**
Evaluating the Deaf Nest: Deaf awareness study day that has been designed to ‘Improve maternity care for Deaf parents’.

This questionnaire aims to assess participant knowledge in relation to deaf awareness. The purpose is to assess effectiveness of the deaf awareness study day in developing the knowledge about providing care to deaf parents within midwifery practice. If effective, the intention is to use deaf awareness study days to educate student midwives and qualified midwives in the arena of deaf awareness.

The delegates were asked to score in a scale from 1 to 10 of how much they think they know about deafness before and after the conference. The average score before the conference was equal 4 and average score after the conference was equal 7. The results of the evaluation will provide evidence-based information to both students and qualified midwives about deaf awareness in maternity care. The aim is to publish the findings without personally naming participants in any of the reports. The results of the Understanding Deafness Evaluation Tool (UDET) are presented on the following pages.

The average score of deafness awareness before the conference was equal 4 and average score after the conference was equal 7.
Communication

88% of delegates couldn’t name rules of effective communication prior the conference.

The results of the Understanding Deafness Evaluation Tool (UDET) show that 88% of delegates prior to the Deaf Nest conference was not able to instantly classify ten golden rules of effective communication with deaf or hard of hearing people. Only 12% of delegates felt confident and listed all ten rules.

65% of delegates were able to list ten golden rules after conference.

After attending the Deaf Nest conference which consisted of morning presentations and afternoon deaf awareness workshops, 65% of delegates could list ten golden rules of effective communication with deaf or hard of hearing people. Moreover, 35% felt that they still need to build on their confidence when communicating with deaf or hard of hearing people.
‘D’ OR ‘d’?

Prior the conference 21% of delegates knew the difference between deaf spelled with capital ‘D’ and lower case ‘d’.

After the conference 74% of delegates knew the difference between deaf spelled with capital ‘D’ and lower case ‘d’.

- Prior the Deaf Nest Project conference only 21% of delegates could critically discuss the difference between deaf spelled with capital ‘D’ and deaf spelled with lower case ‘d’.
- Massive 79% of delegates did not know what is the difference between ‘D’ and ‘d’.

- After the Deaf Nest Project conference 74% of delegates could critically discuss the difference between deaf spelled with capital ‘D’ and deaf spelled with lower case ‘d’.
- 26% of delegates did not understand the difference even though it was covered in the speaker’s presentations, they felt it would benefit with more in depth explanation.
- Some of the delegates felt that they would like to know more about the difference and cultural and disability context but in context of a single day conference this was not feasible.
75% of delegates felt not confident about providing care to deaf or hard of hearing women.

87.5% of delegates felt confident about providing care to deaf or hard of hearing women.

Prior attending the Deaf Nest conference 75% of delegates didn’t feel they know enough to confidently provide care to deaf or hard of hearing women and their families.

After attending the Deaf Nest conference a massive 90% of delegates felt more confident about providing care to deaf or hard of hearing women and their families.
25% felt confident to work with BSL interpreter.

60% felt confident to work with BSL interpreter.

Prior attending the Deaf Nest conference 25% of delegates could list ten golden rules of effective working with professional British Sign Language interpreter.

After attending the Deaf Nest conference 60% of delegates felt more confident about working with British Sign Language interpreter and could list rules of effective collaboration.
ASSESSING NEEDS

75% of delegates couldn’t assess deaf woman’s needs prior the conference.

The results show that 75% of delegates prior to the Deaf Nest conference couldn’t completely assess a women/ partner/ family about their communication requirements and adapt care to accommodate their individual needs. 25% of delegates felt they could start the process and seek advice from other professionals or people involved in their lives when unable to communicate effectively.

84% of delegates felt confident to assess deaf woman’s needs after the conference.

The results show that after the Deaf Nest conference 84% of delegates felt more confident to completely assess a women/ partner/family about their communication requirements and adapt care to accommodate their individual needs. 16% of delegates have learnt a great deal about available services to access but haven’t felt confident enough to assess woman’s communication requirements.

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WITHOUT ASSESSING INDIVIDUAL NEEDS, THERE IS NO CARE
54% of delegates wasn’t aware of the challenges deaf and hard of hearing parents face.

54% of delegates wasn’t aware of the challenges deaf and hard of hearing parents face in their journey into parenthood. They understood that there will be some challenges but they were unaware of the full extent of these challenges. Moreover, they were unaware of the inequalities deaf parents face and they recognised the need to develop their knowledge and skills in that area in order to provide individualised and holistic care to deaf women and their families.

98% of delegates are now aware of the challenges deaf and hard of hearing parents face.

After the Deaf Nest conference 98% of delegates felt that they are aware of the challenges deaf and hard of hearing parents face in their journey into parenthood. The event has opened their eyes and raised awareness of maternity services and the inequalities that deaf parents face when accessing health services. They feel less ignorant and think about the challenges faced by deaf parents. Some of the delegates made learning sign language as a long term goal in their personal development portoflios.
The Deaf Nest Project is a ground breaking achievement in both the Deaf and midwifery community.

Janice Connolly, Deaf Health Champions, Volunteer Co-ordinator - Merseyside explains:

‘The impact that this project can potentially have on maternity provision within the Deaf community is tremendous. I only have to draw on my own experiences to remember the terrible experience of pregnancy and accessing services. When conferring with other Deaf parents the traumatic tales are all too similar. Parents have been left frightened by limited information, no communication provision and a general lack of understanding about the culture of Deaf people. It is refreshing to see the Deaf Nest project aiming to change this situation.’

Jonathan Swift, Deaf Health Champions, Acting Project Manager said:

‘In my opinion the Deaf Nest project is a ground breaking achievement in both the Deaf and midwifery community, and has the potential have a huge impact on addressing the huge inequalities that exist for Deaf parents of the future. As with all areas of Health & Social Care, it is much evidenced through the project that antenatal and postnatal services are frequently failing to meet the basic needs of Deaf mothers and fathers that relate to to their unique communication, linguistic and cultural needs. The project has already won a national award in public health from the Royal College of Midwives, which in itself is huge achievement. The Deaf Health Champions project, which is managed by SignHealth fully supports the Deaf Nest project in attempting to tackle the injustices that exist in maternity provision for deaf parents.’
Joanne Slater

*Project Manager for the Deaf Health Champions*

*UK Council of Deafness*

Deaf Health Champions is a project in the North West of England which brings together deaf volunteers with healthcare professionals – primarily within Clinical Commissioning Groups and local Healthwatch organisations. Our aim is to improve the healthcare experience of deaf patients, ensure equality of access to services and to improve the health of all deaf people. It is a pilot project funded by the Department of Health’s Volunteering Fund until December 2015. We are a partnership of five leading deaf charities; UK Council on Deafness, SignHealth, Manchester Deaf Centre, Deaf Vision Cumbria and Merseyside Society for Deaf People.

I initially thought the Deaf Nest Project was a research paper highlighting the plight of deaf parents. What the Deaf Nest Project has become is a real vehicle for change.

Organisations do endeavour to treat patients equally, however the reality is that profoundly deaf people generally do not receive the same level of care as everyone else. Although the Deaf community are resilient and always optimistic for change, often they become resigned to poor care.

I initially thought the Deaf Nest Project was a research paper highlighting the plight of deaf parents. What the Deaf Nest Project has become is a real vehicle for change. One extraordinary woman has delivered research from deaf people, actual resources for deaf people, training materials for health students and professionals. She has brought the barriers deaf people experience to a national platform and is a worthy winner of the many awards in recognition of her work.
Jacque Gerrard is the RCM Director for England. Jacque qualified as a registered nurse in Glasgow in 1981 and moved to Yorkshire soon after to start married life. She qualified in 1983 as a Midwife at Bradford Hospitals NHSFT. In 1991 Jacque graduated with her MSc in Nursing studies at the University of Bradford. In 1995 Jacque took some time out to care for her twin sons and do her “apprenticeship” in Motherhood! She then went on to become the Head of Midwifery in Leeds Infirmary and two other large Trusts in the North of England including Bradford Hospitals NHSFT and also Calderdale and Huddersfield NHS FT. In August 2008 Jacque left the NHS to further widen her Horizons’ and contribute to influencing the National Maternity picture by being appointed as the Director for the RCM in England. Jacque represents the RCM on a number of Regional and National Forums where she inputs and influences the National Maternity agenda and policy development on behalf of the RCM. Part of the job involves traveling across the four corners of England to meet midwives, student midwives and support staff who provide care to women and their families. Jacque engages with the wider NHS including Heads of midwifery services, HEE,PHE,DH and NHSE as well as working with other Royal colleges and key stakeholders including women’s groups.

Jacque particularly enjoys time spent with student midwives providing honorary teaching sessions in some of the HEIs including, Bradford, Leeds, Salford, Edge Hill and University of Hertfordshire discussing policy, politics and safe high quality maternity care. More recently Jacque has become involved in the RCM international and Global strategy and leads on the RCM Cambodian/England Global Midwifery Twinning Project where the RCM has twinned with the Cambodian Midwives Association. Jacque was awarded an honorary degree (Doctor of the University) by the University of Bradford on 16 July 2014 which Jacque was delighted to accept.
The award winning Deaf Nest project is a unique example of best practice in how to break down the barriers that exist in the NHS for pregnant deaf women.

At a time of change where maternity services in the NHS are aspiring to deliver safe high quality maternity care for all women, the challenges of delivering equitable care to women who have hearing problems and are deaf is a challenge that midwives, student midwives and support workers need to overcome. The award winning Deaf Nest project is a unique example of best practice in how to break down the barriers that exist in the NHS for pregnant deaf women by raising awareness and offering solutions which can potentially be mainstreamed into the NHS maternity pathway. The aims of the project are to highlight how simple measures can be put in place to support women who are deaf and pregnant, access a full range of maternity care and improve the experience of care whilst having healthy outcomes. The project is a perfect example of NHS England’s 6Cs – Care, Compassion, Competence, Courage, Commitment and the biggest one of all for pregnant deaf women Communication, is key to the success of the project.

By improving communication and developing more inclusive services for deaf and pregnant women as highlighted in the Deaf Nest project, women and their families will be empowered and more confident in accessing midwives and health care professionals. This will in turn result in women having a positive birth experience as well as healthier and better outcomes.

Developed by a student midwife, who has not yet completed her midwifery education, the Deaf Nest Project is an outstanding example of how to deliver a compassionate caring maternity service to a group of women who are vulnerable, face challenges and barriers to maternity care. The Royal College of Midwives congratulate the project founder Paulina Sporek, and we look forward to seeing the Deaf Nest project spread widely for pregnant deaf women in the NHS.

The Deaf Nest Project is an outstanding example of how to deliver a compassionate caring maternity service to a group of women who are vulnerable.
‘I found this conference inspiring as well as educational.’

‘Today has most definitely prompted me to think about my communication practice as a professional. I feel much more aware of how I would possibly be able to promote communication needs and to provide a holistic and individualised care to deaf parents on their journey into parenthood.’

‘It has really opened my eyes and raised awareness of maternity services and the inequalities that Deaf people face when they access health services.’

‘I have made learning sign language as a long term goal in my personal development portfolio. I would like to increase my knowledge further.’

‘Informative, interesting and stories were inspirational.’

‘It was a very informative conference with amazing speakers and I would definitely come along to the next one.’

‘Fantastic conference- let’s get other health professionals involved- not just midwives.’
The Royal College of Midwives, the Slimming Award for Public Health

This award recognises an individual or team who have developed and led an initiative that has secured measurable improvements in the delivery of public health outcomes and health promotion in the community. The award recognises the demonstration of a high level of working with other agencies and user groups.

The Cavell Nurses’ Trust

This award recognises the enthusiasm and willingness to question practice that students bring to midwifery. It recognises professional attitude, a love of midwifery, acting as an advocate for women throughout their birth experience and acting as a role model to others.

The British Journal of Midwifery Award

This award recognises the enthusiasm and willingness to question practice that students bring to midwifery. The winner of this award will be invited to join the BJM Editorial board for 1 year.

The Iolanthe Midwifery Trust, the Ann Stewart Award

The Ann Stewart Award is given each year to the award winner who, in the view of the Trustees, reflects the greatest commitment to, or development in, midwifery practice.

The Enei, the Community Impact Award

The Employers Network for Equality & Inclusion is the UK’s leading employer network covering all aspects of equality and inclusion. The award recognises projects that have reached out to and engaged disadvantaged minority group.
Good parenting starts in pregnancy. What child experiences during their early years, starting in the womb, lays the foundations for the whole of their life.

The Deaf Nest Project believes that good parenting starts in pregnancy and it brings real and lasting benefits to child’s emotional, physical and social development. All parents need help and support at some stage, from having a healthy pregnancy and breastfeeding to understanding child’s behaviour. This is no different for deaf parents and the Deaf Nest Project seeks to produce resources with evidence-based information available for free on the deafnest.com website.
Midwives and other health professionals need access to regular good quality training in deaf awareness.

There is no doubt that midwives and other health professionals need access to regular good quality training in deaf awareness. The Deaf Nest Project in collaboration with supporting national and local Deaf charities, namely the Deaf Health Champions, the Sign Health, the Diverse Signs and the Genie Networks has introduced first Deaf awareness conference held in the University of Salford. The event like this helps practitioners to share good practice and knowledge, exchange ideas and become familiar with local and national charities.

Training and workshops are aimed at the multidisciplinary teams across gynaecology and maternity services, but consideration should also be given to ancillary and support staff who are often on the side lines.

It is hoped that in the future deaf Awareness will be offered to midwifery and nursing students as a part of their training programmes.
GOOD PRACTICE

Deaf people ‘suffering’ from discrimination, not ‘suffering’ from deafness.

The public health role of the midwife is recognised as being central to supporting women’s physical, social, and psychological wellbeing (O’Luanaigh & Carlson, 2005). The guidance of professional conduct (NMC, 2008) stresses the importance of facilitating choice, control and woman-centred care. This is further emphasised by the Disability Discrimination Act 1995 (DDA, 1995) with its reference to the duty of care concerning access, quality of service, communication and disability awareness. The key principle here is an understanding of the problems faced by deaf women and their families when accessing maternity services (Jackson, 2011). Deaf and hearing-impaired parents are a disadvantaged group (Deaf Parenting UK, 2007). Consequently, it is more important than ever that midwives contribute to the development of appropriate policies that protect deaf women’s autonomy and ensure equal access to all services without barriers (Bramwell et al., 2000).

Deaf and hearing impaired parents are a disadvantaged group.

Midwives must adopt a position of ‘determined advocacy’ (Oliver & Sapley, 1999) for women’s civil rights under protective laws such as the Disability Discrimination Act 1995 (DDA, 1995) and the Equality Act (2010), and be prepared to assume non-traditional roles (Fusick, 2008). An essential component of midwifery care is to protect deaf women’s dignity. The basis for this component includes trust, ongoing dialogue, enduring presence and shared responsibility (Berg, 2005).
In partnership with the charitable organisations the Deaf Nest Project will undertake following steps:

1. Set up mechanisms to actively encourage the sharing of best practice for deaf parents.

2. Continue to work in a close partnership with local and national deaf charities.

3. Review ways of engaging with deaf parents to seek feedback on their experience of parenthood.

4. Work in a collaboration with Software Engineering Department to design a new software to transfer sound of fetal heartbeat to vision and vibrations.

5. Work in a collaboration with video and audio production to produce “Deaf Nest” documentary about the challenges deaf people face on their journey into the parenthood.

6. Produce guidance and support pack for midwives, including quick reference diagrams.

7. Produce communication aids for deaf parents, including quick reference flash cards.

8. Produce videos with British Sign Language Interpreter containing information about antenatal, intrapartum and postnatal periods. These will be available to access for free on the deafnest.com website.

9. To promote the Deaf Nest Project via Facebook, Twitter and Youtube.

10. Widen the scope of work to include support for hearing parents who have deaf children.
Become the Deaf Nest Ambassador

Deaf Nest is looking for volunteer ambassadors. We need people who are friends and supporters of the Deaf Nest project, and who can be the face of the project their communities across the England. Ambassadors are passionate volunteers and influential supporters, across a wide range of industries and regional areas that help forge fundraising relationships and raise awareness of deafness awareness. They use their professional skills to assist the project, create opportunities for the project to raise money or profile, represent the project in the media when asked and attend events and encourages others to do so.

Become the Deaf Nest Champion

People choose to volunteer for a variety of reasons. For some it offers the chance to give something back to the community or make a difference to the people around them. For others it provides an opportunity to develop new skills or build on existing experience and knowledge. Regardless of the motivation, what unites them all is that they find it both challenging and rewarding. Would you like to become Deaf Nest Champion?

Sponsor

Deaf Nest is looking for organisations and companies who would be happy to sponsor the project and help me in my attempts to improve maternity care for Deaf parents. Deaf Nest Project is very cost effective and volunteer led. However, funding is needed to create resources packs for midwives and Deaf parents. Sponsor and make a huge difference in improving maternity care provided to Deaf parents.

Share

Share project with others and spread the world about Deaf Nest using wide range of media.
REFERENCES


REFERENCES


