PROPOSAL

Improving childbirth and pregnancy experience for a deaf couple.

Empowering, Enabling and Supporting.

With Support of:

UK Council on Deafness
Cumbria-DeafVision
Manchester Deaf Centre

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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). It has significant personal (Royal National Institute for the Deaf, 2011) and social costs (Shleld, 2006). What evidence is available indicate poorer physical health among deaf people (Sign Health, 2008). Kochln and Rogln (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.

Deafness/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 D/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 (Bramwell, Harrington &
Harris, 2000). 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 D/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 D/deaf women, Atkin et al. (2002), state that D/deafness presents additional barriers such as being socially and morally more vulnerable. D/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.
Facts

- Hearing loss currently affects more than 10 million people in the UK. 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 under-researched and unrecognised.
- 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.

(The Royal National Institute for Deaf People, 2011)

- Based on statistics from 1992, midwives are caring for approximately 700 deaf women who gave birth in the UK every year and this number is raising every year.

(Devlin, 1992)
Primary Objectives

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

- Promote deaf awareness for midwives 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 (this will involve setting up a consultation group in the Manchester Deaf Centre).

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

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

- Provide accessible and accurate up-to-date information to enable informed choice.

Statement of Need

There is little literature available on providing maternity care to deaf women and their families (Bramwell; Harrington & Harris, 2000). The lack of relevant literature suggests that deafness and pregnancy are two concepts rarely considered together. Is it assumed then that deaf women do not want to become parents? (Rotheram, 2007). Despite the most recently available statistic which shows a dramatic increase in hearing loss, a little has been said or done in relation to pregnancy and childbirth. The pregnancy book available cost of £14.99 for deaf parents, 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.

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 D/deaf women and their families when accessing maternity services (Jackson, 2011). D/deaf and hearing-impaired parents are disadvantaged group (Deaf Parenting UK, 2007). Consequently, it is more important that ever that midwives contribute to the development of appropriate policies that protect D/deaf women’s autonomy and ensure equal access to all services without barriers (Bramwell et al., 2000).

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 D/deaf women’s dignity. The basis for this component includes trust, ongoing dialogue, enduring presence and shared responsibility (Berg, 2005). Jackson (2011) in her research into D/deaf women’s experience of maternity services concluded that many D/deaf women would like to be included in the normal care provision and that continuity of care it’s an
important factor to achieving a woman-centred approach. Similarly, the Royal College of Midwives (RMC, 2008) stated that every woman has the right to receive individualised, safe and high quality maternity care. The Royal National Institute for Deaf People survey (2004) of patient experiences certainly supports this view.

Moreover, Williams & Martin (2006) emphasise the careful thought 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 (Wates, 2005) in order to provide midwifery care tailored to the individual needs (Brown, 2003). This perspective in relation to D/deafness leads to use of professional interpretation services as highlighted in the latest CMACE (2011) report. Midwives must acknowledge the limitations of their own competence, knowledge and scope of professional practice (NMC, 2012), and ensure the presence of a British Sign Language interpreter to allow D/deaf women to fully access the information available to them (RCN, 2007; NMC, 2008). 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 (NMC, 2012). In the absence of an interpreter, midwives need to be innovative in enhancing their communication skills (McKay-Moffat, 2007). ‘Midwives can learn sign language’ (Kelsall et al., 1992). This is not to replace the interpreter but to enable basic communication when the interpreter is not present (McAleer, 2006).

Finally, there needs to be more awareness among midwives about caring for women with unseen disabilities, such as D/deafness (Lynn, 2008). The challenge is not only to see each woman as an individual but to also be aware of the impact impairment may have on her life (McKay-Moffat, 2007). The first recommendation concerns the importance of taking a positive approach to the pregnancy of a D/deaf woman where emotional support is as important as practical support (Rogers, 2006). 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 (NHS Commissioning Board website, 2012).
**Project Description**

I submit a proposal for ‘Deaf Nest’ project, ‘Improving childbirth and pregnancy experience for a deaf couple’. The project to be initially delivered in partnership with Manchester Deaf Centre and ‘Deaf Health Champions’ whose aim is to ‘improve personal experience, equality of access, choice and control over health care for D/deaf people’. ‘Deaf Health Champions’ similar to ‘Deaf Nest’ share the same values and recognise that Deaf people experience communication barrier and are often excluded from health and social care. It was agreed support from partner agencies including: Manchester Deaf Centre, UK Council on Deafness, Sign Health, Merseyside Society for Deaf People and Deaf Vision Cumbria, to ensure quality and effectiveness of program.

The ‘Deaf Nest’ project includes components designed to ensure dignity and address deaf couple’s needs in the journey of childbirth. One important component is to set up a consultation group in the Manchester Deaf Centre to make sure woman’s and family’s ‘voice’ is heard. This involves communicating and listening to Deaf people experience of childbirth and involving them to bring about change. First pilot group will commence in June 2013 and will be delivered in duration of 6 weeks. The pilot group will be then evaluated and final consultation group planner for future groups will be produced in order to start sessions in Merseyside and Cumbria run by local volunteers. The pilot group consist of two parts. First is educating Deaf parents and the second is educating midwives and other maternity health professionals.

Integral to this is promoting deaf awareness for midwives by organising regular workshops, service users days and conferences. The main purpose of midwife role in the project will be to bring evidence-based, expertise knowledge to the program.

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.
Additionally, project seeks to:

- Create, www.deafnest.com - website with all learning materials produced and obtained from other supporting agencies. These will include: videos, leaflets, guidance, pictures, recent news. The primary objective is to create a space where all information will be available for free for deaf people as well as health professionals.
- To promote ‘deafNest’ via Facebook, Twitter and youtube.
- Organise 1st Study Day of Deafness Awareness for Midwives in the University of Salford on 9th of April 2014.
- Work in a collaboration with Youth Group from Manchester Deaf Center to produce promotional video ‘Every child matter’, with deaf children signing the song using British Sign Language.
- 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.
- Produce videos with British Sign Language Interpreter.
- Produce guidance and support pack for midwives, including quick reference diagrams.
- Produce communication aids for deaf parents, including quick reference flash cards.
- Organise fundraising event and use money to produce ‘deafNest’ pack to be available for each Trust nationally.
Hearing loss currently affects people

10 MLN

Deaf

Deaf nest

DEAF

AVOCACY

dignity

COMMUNICATION

DEAF CHAMPIONS

deafnest.com

It is estimated that by 2031, people in the UK will have hearing loss.

14-5 MLN

DEAF

DEAF

referral, guidances, visual aids

RESOURCES

Lack of literature suggest that deafness and pregnancy are two concepts rarely considered together. Hearing loss is underresearched and unrecognized.

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Evidence Based Practice

Join up care with integrated multi-disciplinary team in order to provide midwifery care tailored to the individual's needs.

Overcome Barriers

To see each woman as an individual and be aware of the impact impairment may have on her life.

Resources

Referral, guidances, visual aids

Research

Joined-up Care

produce communication aids for deaf parents and support packs for midwives.

Partnership

Individualised

Communication

Deafness Awareness

*Deaf Nest*: Improving childbirth and pregnancy experience for a deaf couple.

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Conclusion

This paper has given an account of the principles on which the ‘Deaf Nest’ project will be based. One of the most significant findings to emerge from this project is the importance of taking the time to understand women’s concerns and adjusting the practice to incorporate the unique needs of Deaf families (Jackson, 2011). This underpinning knowledge is essential to achieve woman-centred and individualised care.

Midwives are autonomous practitioners accountable for the standard of care they provide. They are legally and professionally obligated to establish and maintain a relationship based on trust with those in their care. Moreover, they play a key role in exchanging information and understand deaf women’s needs in order to act as an advocate and helping to overcome the barriers than can be created by deafness (Jackson, 2011).

Pregnancy and motherhood are major life events for all women, not least for D/deaf women. Nevertheless, D/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 (McKay-Moffat & Rotheram, 2007). ‘Deafness implies diversity, and diversity in relation to hearing loss needs to be acknowledged, understood and, most importantly, respected’ (Munoz-Baell & Ruiz, 2000, p. 44).

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References


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