

## **Involvement in Midwifery Education: experiences from a university carer and service user partnership**

The X Partnership was established in 2004 within a UK University qualifying social work programme and extended across the Faculty of Health and Social Sciences in 2011. The partnership employs two service user and carer coordinators and has over 90 members who are experts by experience and who contribute across the faculty to the design and delivery of lectures, assessment panels, role plays and simulation, admissions, curriculum design and research. Over a typical year, we coordinate over 900 contact hours between students and service users in addition to the direct contact students have in placement settings.

Involving women in midwifery education however has been a challenge. Time can be particularly precious to expectant and new mothers. Childcare responsibilities often preclude parents from attending university settings to contribute to the design and delivery of a programme or to participate in interview panels and by their very nature; expectant and new mothers are a transient group in terms of their recent experience of using maternity services. There is little existing literature from the midwifery field sharing and evaluating the impact of different models of involvement on students' learning and subsequent practice or of ways of overcoming these challenges.

The aim of this paper is to provide a critical reflection on the experiences of X Partnership in addressing these challenges through the development of three key approaches to meaningfully involving women and their families in pre-registration midwifery education:

1. use of social media and consulting with community groups and organisations
2. direct involvement
3. developing digital resources

### Rationale

Over the last decade there has been increasing recognition of the importance of involving service users and carers in health care professional education and research (Health Foundation 2011) and how involvement and embedding first hand

experiences and perspectives can be used effectively to enable students to consider the impact of their practice on women and their families. The Nursing and Midwifery Council (NMC) provides standards for Pre-registration Midwifery Education and one of its recommendations is that the Lead Midwife for Education (LME) employed by an approved educational institution involves service users and user groups within midwifery programmes of education (NMC 2009). There is no specific guidance however on how this should be achieved or to what purpose. A lack of clear guidance can place the onus on universities to be creative in developing involvement which is meaningful, but can also lead to minimal and tokenistic practice if the purpose and impact is not clear.

In an attempt to differentiate between levels of involvement in mental health education, Tew et al (2004) developed the ladder of involvement. Level 1 was described as no involvement or consultation; level two: limited involvement; level three: growing involvement; level four: collaboration and the gold standard level five: partnership, where service users, carers and teaching staff work systematically and strategically across all areas of course planning, delivery, assessment, management and evaluation.

The ladder of involvement provides a useful tool from which to evaluate the nature of involvement. As a partnership, we operate predominantly at level five but acknowledge that the extent of our collaborations differ across the health and social work programmes we work with. Our involvement in midwifery programmes is currently identified as level three: 'growing involvement' where the partnership is routinely involved in planning and delivery of sessions within units and the admissions process. This will be considered as we reflect on different models of collaboration and involvement in this paper.

The need for involvement and for this to be meaningfully delivered through collaborations and partnerships is widely evidenced. Through our partnership's own evaluations of involvement across a range of health and social care disciplines, students have identified significant impact of having service users contributing to and shaping their education. A thematic analysis of over 2,000 evaluation forms collected in a two year period from nursing, midwifery, allied health professions and social work students, showed three key benefits:

- emotional impact and the ability to hear and explore first hand and sometimes difficult experiences and develop insight and resilience
- knowledge impact and the opportunity to better understand and apply theory such as grief and loss
- practical impact and the opportunity to identify specific changes students can make to improve their practice and the outcomes for service users and their families.

Further evaluation is needed to identify the extent of the impact beyond the sessions and whether students make changes to their practice as a result. In a study the partnership conducted into the impact of social work students' subsequent practice (author's own 2016), findings showed that the impact was individual to each student. Types of involvement perceived as having the most significant impact, particular when students encountered something similar once qualified, where activities which involved conversations with service users and the opportunity to receive feedback on their practice.

Organisations such as the Association of Improvement of Maternity Services (AIMS) which have been reporting on women's experiences of maternity care for many years, report that women value holistic midwifery care and above all a midwife who listens to their views and is non-judgemental (AIMS, 2012). Midwifery students in the UK spend up to 50% of their time in practice working with women during pregnancy and childbirth; therefore it is incumbent that an appropriate strategy should be in place to both select applicants to pre-registration programmes who demonstrate these qualities and to engage in activities to foster these qualities in students throughout their programme. Collaborating with service users can ensure that this goal is achieved by creating a culture which recognises the expertise of people with first hand experiences.

Despite the emphasis on personal and professional qualities and the need for service users to be involved in midwifery education in the UK, there have been few studies on the subject other than in relation to involvement in selection interviews (Long 2010, Jay 2012). Studies such as Jha et al (2009) however, report high student satisfaction associated with patient involvement in their systematic review of involvement in medical education. Learners feel the sessions are more relevant to

them, and that they enhance their understanding of patient perspectives. They believe patient contact improves their communication skills and increases their confidence in talking to patients. This replicates the findings of many studies in other health and social care disciplines (e.g. O'Donnell and Gormley 2013, Webber and Robinson 2012, Tew et al 2012, Authors own 2012). This suggests the need for universities to prioritise the development of partnership working across the curriculum as well as in informing the process for selection of applicants to pre-registration programmes.

In addition to the impact on students and their subsequent practice, there is evidence that this is reciprocal in nature. Patients have reported feeling that their experience of illness and the healthcare system should be included in medical and health education (Stacy & Spencer, 1999, Walters et al 2003, Muir and Laxton 2012); and those that have contributed, have reported a range of benefits. Walters et al (2003) report specific therapeutic benefits for contributors, such as raised self-esteem and empowerment, development of a coherent 'illness narrative', new insights into their problems and deeper understanding of the doctor-patient relationship. Programmes often receive positive feedback from users, with most wanting to be repeatedly involved. Whilst the rationale for involving experts by experience is clear; collaborating in a meaningful way can be more of a challenge. Ways we have sought to achieve this are presented here.

### **Consulting with women and their families through community groups, organisations and social media – going to them**

As mentioned, a particular challenge of developing involvement in midwifery education has been the transient nature of the service user group and the limited time expectant and new parents have. A particularly successful approach therefore has been to engage with parents through social media and community groups and by adopting a 'we go to them' model of involvement. In addition to a number of research studies within the faculty which have used this approach for consulting with women on research topics and design (for example Grigsby's 2015 midwifery study exploring the use of Aromatherapy), social media was used to consult with women on the development of the midwifery curriculum and in the design of the recruitment

and selection process for entry onto pre-registration midwifery programmes. A review and evaluation of the university's midwifery education provision in 2014 sought views and perspectives from women at stakeholder meetings, parent groups (we attended two mother and baby groups); and through social media sites such as The *discussion board* and *Coffee House chat* at <http://www.mumsnet.com/> and <http://www.netmums.com/> respectively where parents were asked the following:

- What knowledge and skills do you expect from a midwife?
- What personal qualities do you feel a midwife should have?

Responses were received from 78 women who identified themselves as currently in contact with a midwife as a parent or pregnant woman.

Despite the differences in the two questions asked, all the responses focused on personal qualities with few mentioning specific skills or knowledge. Whilst this could suggest that knowledge and skills were lower in priority for the respondents, it more likely suggested that this was accepted as fundamental to the midwifery role and that respondents wanted to stress the importance of personal and professional qualities. In future, creating the opportunity to engage more actively in the discussions and asking follow up and clarifying questions might enable us to develop deeper insights. Not doing this however, enables the respondent to take the lead in what they focus on and prioritise. Emerging themes included midwives being kind, calm and caring; having good communication and treating women as individuals. Respondents talked about the need for the midwife to appreciate how nervous and frightened a woman might feel, particularly if she was expecting her first child or her previous birthing experience was complicated or traumatic. Comments included:

*I think midwives need to be understanding and caring and take time to reassure mums at an exciting, but sometimes rather nervous time!*

*Taking time to listen to each and every pregnant woman's concerns – no fobbing off with 'it's just part of pregnancy', because to that woman; it isn't 'just' anything.*

Themes were very much aligned with the 6 Cs of nursing: Care, Compassion, Courage, Communication, Commitment and Competence (Department of Health 2012) and the humanisation of healthcare agenda (Todres, Galvin and Holloway

2009:68) which emphasise the need 'to place human beings at the centre of care'. Obtaining feedback from women using maternity services enabled us to incorporate these themes in both the curriculum and the practice assessment document(s) and to provide a more lived experience version of the impact of the 6 Cs by sharing the comments with students

A further purpose of involving women through social media was to inform the process of selecting applicants onto midwifery programmes. Jay (2012) and Long (2010) have reported on the advantages of directly involving women in the interviewing of candidates, but this can be a challenge given the large number of applicants being interviewed and the impact on a person's time. To address this, we sought to generate a 'user led' question to be used as part of the interview process drawing on the information provided by women through online forums and community groups. Whilst this approach means that women do not form part of the decision making process on the day, they play a significant part in influencing this process. This is reflective perhaps of level two of Tew et al's (2004) ladder of involvement criteria where service users are consulted with but where key decisions are made elsewhere. A disadvantage of engaging people through social media is that they are not paid for their time, a key principle of the X partnership's work and one of Tew et al's measures for each level. We found the advantage of social media and online forums however to be the involvement of a larger and more diverse group of participants than we could have achieved through direct involvement and the depth and range of thoughts and personal experiences expressed by the women; perhaps because the anonymity affords them the freedom to be open and honest as well as the immediacy by which they could share their comments and discuss these with others.

As a result, midwifery candidates are now asked at interview, 'Which attributes does a student midwife need, to support a new mum to be?' The collated information from the women provides a marking guide for this question. Evaluation from midwifery colleagues identifies that this places particular emphasis on the need for professional values and enables them to explore this with candidates at interview. Further research is needed to compare this with the impact of having service users as part of the interview panel and whether this changes the offer and acceptance decisions made.

## Direct involvement in teaching and learning

In teaching and learning we have been able to develop direct models of involvement by collaborating with parents to contribute, deliver or engage in lectures and seminars. The X partnership sees involvement as an active partnership between service users and carers, academics and students. Teaching sessions are planned in collaboration with the woman or family member to ensure that the students receive a meaningful and relevant learning experience which is linked to the unit's Intended Learning Outcomes (ILO's) and collaborators identify how best to achieve this.

One such example sits within a year two midwifery unit of learning, focussing on the theme of 'grief and loss'. David comes in to talk to students about his experience as a father of a stillborn child, alongside theoretical input from the academic. Students are asked to evaluate the session in terms of their learning and potential impact on their future practice. Comments include:

*Hearing from a personal source; not studies, stats etc. makes the whole experience more human; less clinical.*

*I feel I learnt a lot from today's session and feel much more equipped to deal with stillbirth. There were common themes about communication, making memories and the midwife's role.*

In organising direct involvement, it is also important to ensure that the contributor gains something positive from being involved as previously discussed. David shared his motivation for doing the session and what he gains from it:

*"Fathers go through this too! Midwifery education obviously has to be about the care of, and relationship with, mother and baby. I want to tell my side story and show them how much I was affected, as the father in a bereavement situation. I hope it gives the students an opportunity to learn by real-world experience and example, much as they learn about the more routine aspects of care. When the students are part of this type of situation, it will be difficult, painful, emotionally draining – I can't prepare the student for what it's going to feel like but I can give them a start so it's not such a shock when it happens for real, the first time."*



David is eloquent and talks confidently about his experience. Students have commented that his words give more meaning to the experience of stillbirth than any theoretical session could possibly impart. It is vitally important to ensure that students can take a break if they wish and that support is provided for them if needed. Equally vital, is that David feels supported and listened to. One of the key government drives is to humanise care and we have found that collaborating with parents to design and deliver teaching sessions can provide the essence of what it is like to receive care and enables students the time to reflect on their own experiences of practising. David's session is successful in part due to his use of narrative to describe his and his wife's experience using pictures and telling his story chronologically. Equally poignant are his assertions of what kind of care helped and what actions from health care staff did not. Students report that David's contribution and involvement in their unit, provides them with an invaluable legacy of caring sensitively for future parents experiencing grief and loss and aids their development of emotional resilience.

In the same unit, women from the organisation the "Stillbirth and Neonatal Death Charity" (SANDS) are invited to talk to second year students. They bring mementos of their babies and speak poignantly about their losses. Students through this process can witness the depth of the women's grief and learn not only how this impacts at the time of birth but also the period afterwards. One of the women described how her loss was so profound she wanted to dig up her baby just to hold her. Comments such as these have a profound effect on the students. Involving users can be powerful and dramatic and we have found that strategies need to be in place for both the students and the women to draw on if necessary. This can be acknowledged as part of their learning and the session used to support students to identify and utilise strategies for developing resilience whilst on placement and throughout their career. The women, like David, report that they find collaborating with the university and delivering the sessions to be cathartic and see it as time dedicated to their baby and so mutually advantageous.

Members of the partnership have consistently identified a desire to share with students their views and experiences of different services and types of support so this can inform their practice. In another second year Midwifery unit entitled Case loading Practice, a new mother contributes to a session which seeks to raise student



awareness of the existence of, and importance of, user groups and how they inform maternity service delivery. Eva, who brings her baby with her, shares her own experience of maternity services and provides feedback to students on the impact of individualised care and enabling women to make informed choices. Students evaluate the session highly with comments on what they learnt from the session including:

*Further highlights the importance of allowing women to discuss their previous birth stories so that previous negatives are not repeated and appropriate support given*

*A true insight into what matters to women during labour and to highlight the importance of being a woman's advocate. Plus, take awareness of the birth partner and their views*

*How consent is still NOT being obtained – importance of informed choice*

Our evaluations show that this type of involvement has an impact on students' knowledge and understanding; emotional resilience and development of practical strategies to incorporate into their subsequent practice. As with previous x partnership evaluations, students value the opportunity to engage in conversations and ask questions which they may not have the opportunity to ask when in a practice setting. The aim of the sessions is to value the expertise and knowledge someone with lived experience has which goes beyond that of 'telling their story'. Further evaluation is needed (and is planned) to follow up students at a later stage to identify if their practice changed as a result.

### **Embedding first hand experiences and perspectives into teaching by developing digital resources**

Direct involvement and the opportunities to engage in conversations can have many benefits for students' learning and subsequent practice but is not always practicable or in the interests of the service user. The success of X partnership's work has been to explore a range of innovative ways of involving service users and embedding their perspectives and by providing choice to people as to how they may wish to contribute or be involved. One approach has been to work in partnership with people who are experts by experience to share their expertise through digital stories,

podcasts, audio recordings and short films (available on our website [www.X](http://www.X)). One example in midwifery drew on the work of a midwife and researcher who had conducted a research study using photo-elicitation alongside narrative inquiry to explore mothers' experiences of having a child removed at birth (Marsh 2014, 2015, 2016). We worked in collaboration with the researcher and two students from the Faculty of Media and Communication (a producer and editor) to combine the stories and the images the mothers shared and create a digital story (a series of images with an audio narrative). The narrative was voiced by one of the mothers from the research study. As the midwife researcher explains:

*My research area focused upon the psychological and emotional needs of women, whose previous history warranted the removal of their infant at birth and that of the midwives that provided care for them. The overarching aim of the study was to explore what women perceived their experience to be and ultimately "what was missing" to help support them. It also explored midwives perceptions and experiences of engaging with child protection work and the emotional and physical consequences to them of doing so.*

Whilst an emotionally difficult subject matter to explore, the digital story enables midwifery students and practitioners to do so in a safe and supported environment. The aim is not to shock but to foster critical reflection by using the digital story as a real world case study from which to analyse, explore and to reflect on practice. The collaborative nature of the film and how it was produced is an example of a level four and five collaboration and partnership (Tew et al 2014) and has a legacy in how it can continue to be used. The mothers' narratives provide thoughtful reflections on what worked, what didn't and what practitioners might do differently to improve this experience for others. The digital resource offers flexibility in how and when it can be used and seeks to minimise any negative impact on the service user of sharing a lived experience. In addition to informing midwifery education, the film is also being used for social work students and in midwifery practice to improve outcomes and experiences for women who are subject to child protection proceedings.

Reflections from a Carer and Service User Partnership

Throughout this paper we have sought to share our own experiences and practises and in particular what we have found to work and have most impact on student learning and their subsequent practice. It is fair to say that the involvement of service users and carers in education does not ‘just happen’; and that there are a number of distinct stages to developing meaningful involvement in education from recruitment of potential contributors, preparation and training, support during the session and the opportunity to de-brief and gain feedback after.

There are cost implications of having this degree of involvement and providing the support necessary to do it well. The development of digital resources such as short films, and consulting with people online, provides effective ways of achieving this with limited resources, as long as the same principles of support, planning and collaboration are incorporated when creating them. The benefit of course, is that they can then be shared across networks achieving a much wider reach.

Whilst there is an increasing requirement and expectation to involve service users in the design and delivery of pre-registration programmes, there is very little published work in relation to if and how this is being achieved within midwifery education. It is difficult to gauge if this reflects a lack of activity in this field or a discipline which has been slower to share and evaluate existing activity. Without the opportunity to share these experiences and present different models for peer review, there is a risk that involvement becomes stagnant and at a tokenistic level i.e. tier one and two of Tew et al’s ladder of involvement.

The authors would encourage educators and practitioners to join us in sharing examples so broader studies can be conducted into the range of models and approaches; theoretical underpinning; impact on students’ learning and subsequent practice and what difference this makes to the experiences and outcomes for women and their families in the longer term.

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