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A mixed methods study to develop and pilot a competency assessment tool to support midwifery care of women with intellectual disabilities

Sarah Beake *, Louise L. Clark, Toni Turner, Debra Bick

Kings College London, Florence Nightingale School of Nursing and Midwifery, James Clerk Maxwell Building, 57 Waterloo Road, London SE1 8WA, United Kingdom

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SUMMARY

Background: Recent reports have highlighted the poor quality of health care received by people with intellectual disabilities (otherwise known as 'learning disabilities') in the United Kingdom (UK). UK Confidential Enquiries into maternal deaths have highlighted adverse pregnancy outcomes for women with intellectual disabilities and need for timely and appropriate clinical care.

Objectives: To develop and test a competency assessment tool to support midwifery care of women with intellectual disabilities.

Design: A mixed methods study.

Setting: Large inner city maternity unit.

Participants: Midwives and key experts in intellectual disabilities, maternity policy and midwifery education.

Methods: Phase one comprised a systematic narrative review of the literature. Evidence identified informed *phase two* which included focus groups and interviews. Emergent themes informed the development of a competency assessment tool which was piloted in *phase three.*

Results: Phase one: Four primary research papers and two systematic reviews met the review inclusion criteria. Support to develop parenting skills of women with intellectual disabilities was highlighted as was the need to optimise organisation of maternity services. No studies specifically considered midwifery competencies to support women with intellectual disabilities.

Phase two: 23 midwives attended three focus groups and individual interviews were conducted with national leaders in intellectual disability ($n=6$) and midwifery policy and education ($n=7$). Themes identified included need for individualised care provided by a known midwife, the importance of effective communication skills and need for clear knowledge and understanding of the legislative framework relevant to intellectual disability.

Phase three: A convenience sample of 60 midwives was asked to participate in a pilot study to test the tool, 46 (77%) of whom responded. Thirty midwives (65%) felt *competent* in their ability to recognise intellectual disability and 37 (80%) *competent* or *expert* in understanding women have the right to be offered choice and make informed decisions. A high proportion ($n=40$, 87%) reported *little or no knowledge* regarding consent issues.

Conclusion: Work to inform timely and appropriate care of women with intellectual disability has been neglected in the UK maternity services. Use of a tool could aid assessment of midwifery competencies to support women with intellectual disability and highlight where further midwifery education and development are needed. Evidence of optimal care for women with intellectual disabilities and their families across the continuum of pregnancy and birth is required.

Introduction

Accurate data on the number of people in the UK with intellectual disabilities are difficult to obtain. In 2001, it was estimated that around 210,000 people in England had severe learning disabilities, and about 1.2 million had mild or moderate disability (Department of Health, 2001), sometimes referred to as learning disabilities or mental retardation. Of those individuals with mild to moderate intellectual disabilities, it is estimated that around 7% are parents (Emerson and Hatton, 2004). In Scotland, around 2% of the general population are estimated to have learning disabilities, with around 0.4% having severe or profound learning disability (Scottish Executive, 2000). The number of individuals with borderline intellectual disabilities is unknown as many are undiagnosed, although the condition may impact on day-to-day functioning.

Individuals who have intellectual disabilities experience higher rates of physical health problems and co-morbidity than the general population (Department of Health, 2004; Jansen et al., 2004) with international evidence that access by marginalised groups to healthcare is problematic (Gulliford et al., 2002; Ward et al., 2010). In the UK, the independent inquiry, 'Healthcare for All' (Michael,

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* Corresponding author. Tel.: +44 2078483207.
E-mail addresses: sarah.beake@kcl.ac.uk (S. Beake), louise.l.clark@kcl.ac.uk (L.L. Clark), toni.turner@kcl.ac.uk (T. Turner), debra.bick@kcl.ac.uk (D. Bick).

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2008) and the Parliamentary and Health Services Ombudsman's report 'Six Lives' (2009) highlighted a lack of awareness among National Health Service (NHS) staff of how to make the reasonable adjustments required for the often complex health needs of people with intellectual disabilities. The introduction in the UK of the Disability Discrimination Act (1995) resulted in all health service providers in the UK having a legal obligation to consider the needs of disabled people in the planning and delivery of care, although the impact of this on outcomes of mainstream health care is unknown. The Parliamentary and Health Service Ombudsman (2009) recommended that equality for people with intellectual disabilities may mean that alternative methods of making services available needed to be identified in order to achieve equality of outcomes. Ward et al. (2010) in a study from the USA based on interviews and focus groups with health professionals, parents/guardians and community support workers found that adults with intellectual and/or developmental disabilities in the general population faced healthcare disparities and inequities in four areas: access, knowledge, communication and quality. Similar findings have been identified from studies which have focused on pregnant and postnatal women with intellectual disabilities (Becker et al., 1997; Parish and Huh, 2006).

The exact number of women of childbearing age in the UK with intellectual disabilities or the number of children born to women with these conditions is unknown as many women may not have had their disabilities diagnosed. A study from one county in Sweden identified an incidence rate of 2.12 per 1000 children born each year to women with intellectual disability (Weiber et al., 2011). The reporting of poor access to appropriate maternity services among women with intellectual disabilities (Becker et al., 1997; Parish and Huh, 2006) is of concern given evidence of poorer pregnancy outcomes for these women. This is demonstrated most clearly in the two most recent UK Confidential Enquiries into Maternal Deaths (Lewis, 2007; Centre for Maternal and Child Enquiries (CMACE), 2011) which highlighted cases where women with intellectual disabilities did not have appropriate access to maternity services, and poor management of women with intellectual disabilities who died was identified. Women with intellectual disabilities are particularly vulnerable to the risk of thrombo-embolic disease during and after pregnancy as they may be unable to follow advice on prevention, including need to attend for maternity care or self-administer thrombo-prophylaxis injections (CMACE, 2011). In the most recently published enquiry for the triennium 2006–2008, five of the 18 women who died from thrombo-embolic disease had intellectual disabilities and/or psychiatric illness, four of whom were found to have received sub-standard care (CMACE, 2011). An additional concern was that anti-psychotic medication could lead to weight gain making women more vulnerable to the risk of thrombosis.

In addition to the importance of a midwifery competency tool to detect escalating health problems in women with intellectual disabilities, there is also a need to promote midwifery care and support for women which encourages their independence and autonomy. In a recent small qualitative study from Ireland which explored the pregnancy, postnatal and parenting experiences of 17 women with physical and sensory disabilities (one woman had mild intellectual disabilities and visual impairment), found that whilst women welcomed pregnancy as positive, they encountered mixed reactions to their pregnancy from their partners and families and in some cases, were viewed as 'liabilities' by the health professionals they encountered (Walsh-Gallagher et al., 2012). Furthermore, concerns have been raised about the impact of involvement of the courts in decisions about the custodial rights of parents with intellectual disability and lack of support from the health services until crisis intervention was warranted (Tarleton and Ward, 2007).

The role of the midwife is crucial to the experiences and outcomes of pregnancy among women with intellectual disabilities. Every pregnant woman in the UK will come into contact with a midwife, who in addition to provision of clinical care through contacts during the continuum of pregnancy and birth, is also able to act as an advocate on behalf of a woman and her partner if inter agency input is required (Garrod et al., 2011). The importance of why women need appropriate clinical and supportive care from their midwives and other relevant health professionals is illustrated in the following quote:

> '*A high-risk woman with learning disabilities and very high levels of anxiety developed symptoms of pre-eclampsia, in spite of which she continued to be inappropriately managed in the community. Following the birth, she left hospital against medical advice and, during the post-natal period, became increasingly unwell. She died from disseminating intravascular coagulation some days after birth*'.
> (Garrod et al., 2011, p 150; Centre for Maternal and Child Enquiries (CMACE), 2011, *BJOG 118* (*Suppl. 1*), *1–203*).

Research in Scotland was undertaken to address services in one health board area for pregnant women and parents with learning disabilities. This found that services provided more often than not were dependent on the skills, motivation and commitment of particular individuals rather than as a consequence of a clear pathway of support, with staff frequently lacking appropriate skills and knowledge in relation to learning disabilities (NHS Fife, 2010). A UK government commissioned independent inquiry chaired by Sir Jonathan Michael (2008) recommended that all undergraduate and postgraduate clinical education should include competency based mandatory training in the care of people with intellectual disabilities.

In response to concerns about the content and management of care for this vulnerable group of women in meetings with local clinical colleagues following publication of the CMACE findings (2011), the team were asked to consider how midwifery awareness of the needs of women with ID could be raised. Discussions led to a proposal to develop a competency tool for use by midwives, which would enable any training requirements to be identified. The development and piloting of the tool is reported here. The term intellectual disabilities will be used in the paper, however when citing other papers which have used different technology such as learning disabilities or developmental disabilities, these terms will be included.

Methodology

A mixed methods study was designed, with three distinct phases to collate qualitative and quantitative data, namely a systematic narrative review, focus groups and interviews, and a pilot study of the competency tool to test its acceptability to midwives.

Mixed methods research is increasingly used by health service and social science researchers. It is an approach which enables a focus on research questions embedded within real-life contextual understandings which require multi-level perspectives on the issue of interest. It also enables researchers to integrate or combine different research methods which draw on the strengths of each (Creswell and Plano Clark, 2011). A mixed methods approach was considered appropriate for the current study, given the dearth of evidence to inform the content of the competency tool, the need to capture a range of perspectives including those acknowledged as 'experts' in the field to develop a more complete understanding of the problem and reflect the views of current 'best practice' of those currently responsible for maternity care of women with intellectual disabilities.

The multi-phased study included:

Phase 1	Systematic narrative review of the literature
Phase 2	Focus groups with midwives and interviews with key stakeholders
Phase 3	Development and piloting of the competency assessment tool at one large NHS Trust.

Methods, approaches to analyses and results are presented for each phase in the following section.