Original Research

To what extent are midwives adapting antenatal information for pregnant women with intellectual disabilities? A survey of NHS trusts in England

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Objectives: To identify the existing antenatal information provision practices for pregnant women with intellectual disabilities in England. To identify how practices between and within local supervising authorities differed, and if midwives were adapting standard antenatal information for pregnant women with intellectual disabilities, including examples of accessible information being used.

Study design: Cross-sectional survey.

Methods: All contact supervisors of midwives from acute trusts with maternity services were accessed via the local supervisor of midwives officers' databases and sent a questionnaire. Quantitative data were collated. Associations between trust size, geographical location, antenatal provision and National Institute for Health and Care Excellence guidelines alongside National policy were examined using Fischer's exact test of association.

Results: Contact supervisors of midwives returned a questionnaire on behalf of their trust (74, 53%). The majority worked in maternity units with more than 4000 births a year (50, 66%). Few trusts had a specialist or lead midwife in post for pregnant women with intellectual disabilities (17, 22.9%) but over half (39, 52.7%) reported that their trust had a specialist learning disability nurse in post. Only 28.3% reported availability of post registration training and even fewer (8, 10.8%) had access to written protocols. Less than half reported extra time being offered at the booking (29, 39.1%) or routine antenatal appointments (30. 40.5%). Less than a quarter (17, 22.9%) reported that their trust had routine antenatal written information available in accessible formats.

Conclusion: Reasonable adjustments to standard antenatal information for pregnant women with intellectual disabilities were not common practice. Most trusts did not have local guidelines in place or offer midwives post registration education to help support them in this requirement.

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Introduction

The exact number of parents with an intellectual disability (ID) in England is unknown. It is, however, acknowledged that many people with ID remain hidden to services. The prevalence of people with ID is therefore estimated at between 2% and 3% of the general population.

The authors will adopt the term intellectual disability and learning disability synonymously in this paper. The term learning disability is more widely used in health services in England and is defined as:

A reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development. [p.14]

The term intellectual disability does however help with international recognition as it is a term often promoted by bodies such as the World Health Organisation (WHO).

People with ID have an increased exposure to economic and social disadvantage. These factors can have a negative effect on a pregnant woman’s antenatal health and wellbeing, leading to poorer outcomes for both women and babies compared with the general population. One element of social disadvantage is limited access to information about health. Provision of accessible information can greatly improve patients’ experiences and outcomes—failure to make such reasonable adjustments can have far-reaching negative consequences. Unmet antenatal care needs resulting from difficult or limited access to maternity services can be an issue for women with ID. Access and engagement during the antenatal period is therefore particularly important and offers a key opportunity for midwives to engage with this group of women.

Responsibility rests with maternity providers to consider how best they make their service inclusive. Provision of accessible health information is enshrined in law, policy and guidance and is a core component of antenatal care. Policy documents and guidance mostly offer a narrow definition of accessible information for people with ID, usually with a focus on easy-read resources that have large print, simple vocabulary and pictures. Some examples of making reasonable adjustments by adapting antenatal information to make it more accessible have been reported in the literature; however, it is not clear how widespread these practices are within maternity services in England. This survey is therefore an attempt to contribute to this gap in evidence.

Aim and objectives

The main aim of this survey was to identify midwives existing antenatal information provision practices for pregnant women with ID in England.

The specific objectives of the survey were to identify how practices between and within local supervising authorities (LSAs) differed and if midwives were adapting standard

antenatal information for pregnant women with ID, including examples of accessible information being used.

Methods

This survey is phase I of a three-part sequential mixed methods study. Phase II was designed to capture more in-depth qualitative information about the survey findings. In the first part of phase II, focus groups with midwives and policy makers were held to explore their experiences of adapting information and, enablers and barriers ensuring women have information they can understand during their antenatal care. In the second part of phase II, women with ID who were pregnant or new mothers were interviewed to explore their experiences and opinions of the antenatal information they had been given. The findings from phase II will be reported separately.

In the context of this study, the term survey is used to describe a cross-sectional research design—carried out at one point in time, in which a questionnaire is employed as the data collection tool.

Local supervising authority midwifery officers (LSAMOs) were approached by the first author to provide contact details for the contact supervisors of midwives (CSOMs) in their LSA. All but one LSAMO (n = 9) provided this information for their area. A sampling frame was constructed of all acute NHS trusts in England with maternity services and their corresponding CSOM for the 9 LSAs. The remaining LSAMO agreed to personally forward the survey invite to the CSOMs in that area.

CSOMs from all National Health Service (NHS) acute trusts (secondary care) with maternity services (n = 139 in 2014) in England were then contacted by e-mail (October–November, 2014) and invited to complete the self-administered, electronic, web-based questionnaire. The questionnaire was specifically developed by the first author and included predominantly closed-ended questions. A majority of the questions related to service provision expectations outlined in the National Institute for Health and Care Excellence (NICE) guidance. A systematic review on antenatal care for pregnant women with ID also guided the questionnaire development. Owing to the quantitative nature of the survey, the questions were pre-coded.

The questionnaire was piloted with supervisors of midwives who had strategic knowledge of maternity services, and the survey was then amended slightly following their feedback, to make it as comprehensive as possible. To promote anonymity, participants responded on-line through SurveyMonkey. The landing page of the survey requested the respondent to confirm they had read the introduction and consented to take part. They could then follow the link to the on-line questionnaire.

Descriptive statistics including frequency tables and percentages were compiled. Fisher’s exact test was used during the univariate comparisons. All statistical tests were two-sided and values of P < .05 were considered statistically significant. The statistical package SPSS 22.0 was used to perform the analysis.
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