



## Current evidence on antenatal care provision for women with intellectual disabilities: A systematic review

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### ABSTRACT

**Background:** changing attitudes, alongside integration, more independent living and recognition of rights to family life have meant a steady rise in women with intellectual disabilities becoming pregnant. However, existing evidence shows that women with intellectual disabilities are less likely to seek or attend for regular antenatal care. This population experiences poorer maternal wellbeing and worse pregnancy outcomes compared to the general population, including preterm and low-birthweight babies.

**Purpose:** to identify and review the existing evidence on the provision of antenatal care among women with intellectual disabilities.

**Methods:** a systematic search strategy was formulated using key Medical Sub-Headings terms and related text words for pregnancy, antenatal care and intellectual disability. Comprehensive searches dating back to 1980 using pre-determined criteria followed by a hand search of reference lists and citations were undertaken. Data were extracted using a data extraction form and methodological quality assessed using the framework developed by Caldwell et al. (2011). A three stage textual narrative synthesis was used to integrate the findings from the included studies.

**Results:** searches identified 16 papers that met the inclusion criteria. A majority of the papers focused on women's experience of pregnancy and antenatal care with a paucity of papers identified on midwives knowledge and experience. The four broad themes of the analysis and synthesis performed included: In the Family Way ('I've a baby inside. I've got a life inside of me. '); Knowledge and advocacy ('...everyone was looking at one another and no one was talking to me. '); Midwives educational needs ('...helpful to have guidance...') and Midwives Attitudes ('...women with [intellectual disabilities]...should not be pregnant').

**Key conclusions and implications for practice:** significant gaps in the evidence base were apparent, however evidence was identified which showed that intellectually disabled pregnant women struggle to understand antenatal information communicated during pregnancy which was often text based. Maternity care providers need to make adjustments to their services so that antenatal communication, information and care is appropriate for this group of women. Midwives identified that they lacked knowledge in this area and wanted antenatal guidance on how to meet the care and communication needs of women with intellectual disabilities.

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### Introduction

The exact number of parents with an intellectual disability in the UK is unknown with estimates varying widely from 23,000 to

250,000 (Department of Health and Department for Education and Skills, 2007). Regardless, it is known that there are a 'hidden' number of people with less severe disabilities, unknown to services, giving an estimated prevalence in England of 2% of the general population (Emerson and Hatton, 2004). There are a number of reasons for the lack of reliable data including fragmented services, inadequate records, varied definitions of intellectual disability and the fact that many people with 'mild' or 'borderline' disabilities remain undiagnosed (International Association for the Scientific

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Study of Intellectual Disabilities, 2008). The Valuing People White paper (Department of Health, 2001) defines learning disability as: 'A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with; a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development' (Department of Health, 2001, p.14). The terminology used has evolved over the years in the UK from 'mental retardation' to the current term of 'learning disability'. However 'intellectual disability' will be used throughout this paper, as it is the preferred international term (Emerson and Heslop, 2010).

Deinstitutionalisation since the 1980s has been credited with improving the lives of people with intellectual disabilities (Balogh et al., 2008), with larger numbers of people living in the community. Changing attitudes, alongside integration, more independent living and recognition of rights to family life has meant a steady rise in women with intellectual disabilities becoming pregnant (Tarleton and Ward, 2007). Provision of antenatal care for pregnant women is important as its primary aim is to optimise maternal and fetal wellbeing, alongside maternal and fetal screening, and appropriate medical, psychological or social referral where indicated (National Institute for Health and Care Excellence, 2008). People with intellectual disabilities are affected by an increased exposure to economic and social disadvantage, such as income poverty, social exclusion, poor housing and unemployment (Feldman, 1994; Llewellyn and McConnell, 2002; Llewellyn et al., 2003; Booth and Booth, 2005; Baum and Burns, 2007; Emerson, 2011). These are all factors known to have an adverse effect on health and wellbeing during pregnancy and poorer pregnancy outcomes compared to the general population (Lewis, 2007; Mitra et al., 2015). In addition, people with intellectual disabilities are often socially isolated with poor support networks (Guinea, 2001; Kroese et al., 2002; Llewellyn and McConnell, 2002; McConnell et al., 2003; Baum and Burns, 2007; Aunos et al., 2008; McConnell et al., 2009). Social isolation and poverty have been raised by two Confidential Enquiries into Maternal and Child Health (Lewis, 2007; Centre for Maternal and Child Enquiries, 2011), with women who lived in the poorest circumstances up to seven times more likely to die than women from other demographic groups. These women were also far less likely to seek or attend for regular antenatal care (Lewis, 2007) and women with intellectual disabilities were over represented in the number of women who died of thromboembolic disease, possibly due to unmet health needs (Centre for Maternal and Child Enquiries, 2011).

As midwives are the primary care providers for this group of women antenatally and given the greater potential for poorer clinical outcomes, it is imperative that they are able to recognise and address the needs of this demographic of women and families. This systematic review aimed to address the research question: what is the existing empirical evidence on antenatal care provision for women with intellectual disabilities (ID)? The specific objectives were: (i) to establish what is already known about the antenatal experiences of women with ID including the women's experience of pregnancy and antenatal services, (ii) to find out if women with ID have additional care needs during pregnancy, (iii) to discover what is already known about midwives' knowledge regarding caring for pregnant women with ID.

## Methods

### Search strategy

Initial scoping searches of two databases were undertaken in March 2014 by two of the authors (CH, EP), to test identified search terms against Medical Sub-Headings (MeSH) terms. The final search was agreed by three of the authors (CH, EP, DC) and

used a combination of MeSH terms supplemented with free-text words to identify potentially relevant literature, which allowed for inconsistencies in the indexing practices between databases (Supplementary Table).

Additional references were identified by hand searching the reference lists and citations of relevant papers. Searches of table of contents of the most current issues of the publications Midwifery, British Journal of Learning Disabilities, Journal of Intellectual Disability Research, Journal of Applied Research in Intellectual Disabilities and Journal of Policy and Practice in Intellectual Disabilities were also undertaken to address the time lag associated with indexing tools, a method advocated by Brunton et al. (2012). Full publication lists for two experts in the field were identified and reviewed and personal contact made with them via direct email and through the social networking site ResearchGate. They suggested other researchers who may have published on this topic. Open access repositories and Google Scholar were searched for PhD theses.

### Study selection

Title and abstracts were retrieved and screened for eligibility with any uncertainties checked. For studies not excluded on title and abstract, the full paper was obtained and assessed in more detail against the inclusion and exclusion criteria by one reviewer (CH). Empirical studies and book chapters that included primary research and published from 1980 – May 2014 were included if they reported on pregnancy and antenatal care for women with ID and were written in English. As a wide representation of evidence was sought, studies that employed qualitative, quantitative or mixed methods for data collection and analysis were included. Studies were excluded if they were published prior to 1980 and their focus was solely on women with cognitive or physical disabilities, or involved parenting or aspects of care other than pregnancy. Editorials, letters, book reviews, opinion pieces, commentaries and policy documents were also excluded. Due to the lack of funding for translation services it was necessary to exclude studies that were not written in English.

A second reviewer independently assessed the eligibility of full papers, to estimate agreement on inclusion (EP). To ensure transparency the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) template flow diagram developed by Moher et al. (2009) was used to document the progress of information through the four stages of the systematic review study selection process. A record of decisions made for each paper retrieved as full text, was kept and reasons for exclusion documented.

### Data extraction

A wide set of items were systematically extracted from each included paper and collated on data extraction forms by one reviewer (CH). The data included information recommended by Fleeman and Dundar (2014) on the study design, research question, country, setting, participants, ethical standards, sample, data collection, data analysis, outcomes and the main themes emerging from the analysis including any recommendations. In an attempt to provide consistency of data extraction and agreement between the data extracted and the material in the original study a second reviewer (EP) validated these data extracted for each included paper. Any differences were then resolved through discussion between both reviewers and reference to the original papers, a method suggested by Noyes and Lewin (2011) to advance a systematic review. Data extraction was carried out prior to undertaking quality appraisal firstly to reduce reporting bias and secondly as there was no intention to exclude poor quality studies from the review (Greenhalgh and Brown, 2014). The decision to include all studies irrespective of quality aimed to provide as

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