

Understanding the antenatal care experiences of women who have a learning disability in the UK

Eleanor Priestnall

Year 3, Medicine, University of Exeter
Email: Ep518@exeter.ac.uk



Abstract

This review highlights some of the key issues faced by women with learning disability (WWLD) during pregnancy and makes recommendations for improved practice. Experiences of maternity care among WWLD are mixed: some highlighted best practice but many reported barriers such as lack of reasonable adjustments, poor communication, inadequate training, poor attitudes and presumptive safeguarding decisions. However, the paucity of the existing research available limits transferability. Further qualitative research should be carried out to further understand experiences and ensure saturation of themes are found. Follow up with quantitative research is then required to understand how widespread these issues are.

Abbreviations

IPA - Interpretative phenomenological analysis
LD - Learning disability
WWLD - Women with learning disability

Introduction

Learning disability (LD) is described as a significantly impaired ability to understand new or complex information and learn new skills. Onset is before adulthood and can impact on the ability to cope independently.¹ The impact and limitations of LD vary but may lead to experiencing difficulty with everyday activities such as household tasks, socialising and managing money.² LD has been categorised by the World Health Organization's International Classification of Disease-11 (2018) with the associated prevalence being reported: mild (85%), moderate (10%), severe (3-4%) or profound (1-2%).³

The causes of a LD can be genetic, biological or environmental, or a combination thereof occurring before, during or after birth. Down syndrome is one of the most common causes, however in 30-50% of cases no specific cause is found.⁴

In England, it is estimated there are 297,033 people (0.5%) living with an LD,⁵ however it is likely that numbers of people with LD is higher, with those having milder LD less likely to be identified by services.⁶

Emerson *et al.* (2004), estimated the prevalence of LD in England to be 2.0% when measuring disability by intellectual and adaptive functioning, increasing to 2.5% when using IQ scores.^{7,8}

Since the 1980s, people with LD have been supported to integrate into the community by moving away from hospitals and large institutions with the aim of improving quality of life. This transition has been largely positive with increased independent living, a recognition of the rights of individuals with LD and a shift in attitudes.^{9,10} However, people with LD still face significant health inequalities, have worse health than the general population and face barriers in accessing health care.¹¹ Concerningly, women with LD (WWLD) are up to three times more likely to be a victim of physical abuse, sexual abuse or rape.¹² WWLD are often socially isolated with limited support networks and resources and may also be less able to follow health promotion advice.¹³

These risk factors result in WWLD having poorer pregnancy health:

they are at greater risk of severe pregnancy complications and poor birth outcomes, some of which can be reduced with early intervention.¹⁴ Poorer outcomes include higher rates of pre-eclampsia, low birthweight and a higher proportion of babies admitted to neonatal intensive care.¹⁵ It is therefore important to identify and understand experiences WWLD face and recognise failings in provision so that antenatal care can be improved, and inequalities reduced.

This article aims to discuss maternity care experiences for WWLD. It examines the women's perspectives in order to make recommendations for improved practice.

Methods

Search terms and Boolean operators were used to obtain relevant literature, as described in **Table 1** searching in the following databases: NICE Evidence Search, PubMed (Medline), TRIP and OVID (Medline). Filters were applied to find research in the last 10 years and in the English language only.

Table 1. Search terms and operators.

Search terms	Boolean operator
1. Learning disability* OR Intellectual disability* OR Developmental disability* OR Global developmental delay OR Down* syndrome OR William* syndrome ^a	AND
2. Maternity OR Maternal OR Antenatal OR Prenatal OR Pregnancy OR Expecting OR Midwi*	AND
3. Experience* OR Attitude* OR Knowledge OR Needs	

^aAutism and Fragile X syndrome were not included in these search terms as a lower proportion of people with these conditions have an LD linked to their condition (only 1/3 of women and 1/2 of people for Fragile X syndrome and autism, respectively).²

Results were sorted according to search terms by order of relevance for each database. Titles and abstracts of the first 300 articles were then scanned in each database. Additional articles were found by searching reference lists of relevant papers. Further details of the search results can be found in **Figure 1**.

Women's perspectives

A systematic review by Homeyard *et al.* (2016) reviewed 16 papers of mixed methods and found significant gaps in the evidence base; however it highlighted some key issues and recommendations.¹² Women had difficulty finding out about their pregnancy and found antenatal information (often provided in text form) difficult to understand (including appointment letters and paper records). The research was dependable, using logical and auditable processes. Two reviewers independently assessed papers' eligibility, inclusion and exclusion criteria and quality. However, within the primary studies reported on, researchers did not consistently triangulate their findings among several researchers and data saturation was not always found, thus reducing our confidence in findings.¹³ Additionally, Malouf *et al.* (2017) reported a lack of autonomy and disempowering practices by professionals to be common.¹⁶

Understanding information

The research found that during antenatal appointments, women regularly felt rushed.¹⁶ The women reported being given standard, non-adapted information by their midwives, with some not given

any at all. Those that did receive information in an easy-read format received it from other professionals.¹⁶ Homeyard *et al.* (2016) suggest that

women with mild LD - who are at risk of not being identified by services - may be less likely to receive this support and additionally have difficulty keeping appointments.

This cohort of women can often fall between services.¹³ Findings were consistent across participants and saturation appeared to be reached despite women living in different areas of the UK, indicating reasonable adjustments are not provided as standard. This poses a concern as women could be denied information they need to be able to navigate their pregnancy successfully and learn important parenting skills.¹⁶

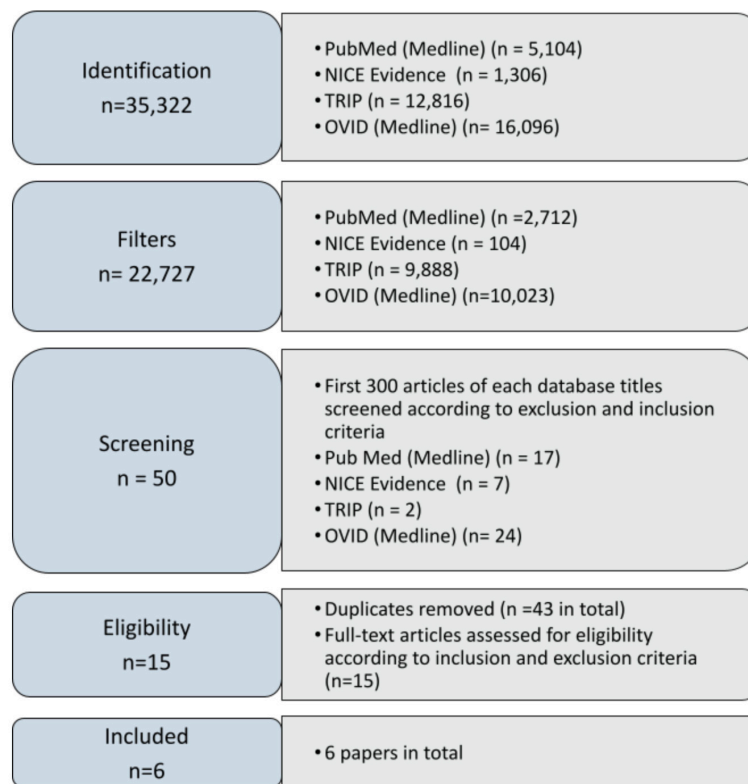
Malouf *et al.* (2017), carried out in depth semi-structured interviews exploring experiences of nine WWLD in the UK.¹⁶ The authors found verbal communication during appointments was mixed, with some women giving positive feedback whilst others reported feeling ignored.¹⁶ Discriminatory attitudes were accepted as being attributed to a lack of staff training highlighting how some WWLD accept the 'status quo' of not being provided with required adjustments/supportive care.¹⁶

Malouf *et al.* (2017), used the analytical technique of 'interpretative phenomenological analysis' (IPA),¹⁵ which aims to provide detailed examinations of personal lived experience, and requires fewer participants to find saturation of themes.¹⁷ The sample demonstrated a fair representation of population disability severity but not of ethnicity, with only Caucasian women participating. Women were recruited by their support workers or midwives. However, this presumes active engagement with services and a higher level of communication as both are needed to offer study consent. The study may not therefore be representative. Furthermore, while the researchers did offer some reflexivity through a manual log, we know little about the interviewer and their background, which may have biased the interview process.¹⁶

These findings are reinforced by the results of a postal survey analysis on maternity care which was sent to over 50,000 women, three months after giving birth; 24,155 responded, of which 120 were WWLD.¹⁸ However, it was not stated whether an easy read format was included therefore potentially biasing findings towards women with a milder LD. Redshaw *et al.* (2013) analysed the results from a disability perspective.¹⁷ The analysis found a smaller proportion of WWLD compared to non-disabled women reported positive experiences: 66% vs. 84% were "always spoken to in a way they could understand", 63% vs. 74% were "involved in decisions about their care" and 58% vs. 73% were "always given help after contacting a midwife". Despite a smaller percentage of WWLD having positive views of aspects of their maternity care, 93% rated their overall antenatal care as good or better.¹⁸



Figure 1. Search strategy results.



Attitudes and autonomy

Women in the study by Malouf *et al.* (2017) had mixed views on how supported they felt by health and social care professionals.¹⁵ Most reported midwives being helpful, friendly and respecting their right to make choices in their maternity care.¹⁶ However, there were instances where health professionals, relatives and authorities restricted and sometimes violated women's autonomy to make their own decisions.¹⁹ Some felt their social workers would support rather than scrutinise whilst others reported they had little encouragement, assumptions were made and that they had to "watch over (their) shoulder".¹⁶ This caused some women to feel uncomfortable with disclosing their disability.¹⁹

Findings by Potvin *et al.* (2019) and Homeyard *et al.* (2016) described how professionals that knew the women provided long term support, facilitated better communication and had encouraging and non-judgemental attitudes.^{13,20} Positive attitudes amongst medical staff were perceived to be attributed to 'help seeking behaviours', diagnosis, age and mental illness by WWLD. Jamieson *et al.* (2016) describe how fear or previous negative experiences can lead to reduced engagement and to women seeking help late in pregnancy.²⁰ This negatively impacts on support and safeguarding decisions made around their care and reinforces negative attitudes amongst professionals.²¹

Safeguarding decisions

Studies suggest the removal of children from parents with an LD is commonly as a result of prejudiced ideas around disability rather than the protection of the child or inability to parent.²² Castell *et al.* (2016) reported that midwives desire to deliver the best care they could and demonstrated beliefs that WWLD had the right to be parents but required extra support.²³ Midwives felt support was available but not readily accessible. Midwives acknowledged that support can make a difference in the outcome of safeguarding however all assumed safeguarding procedures were an "inevitable" part of the pregnancy process for WWLD.²³ Many considered that the process could be done more sensitively, appropriately and with less pressure for WWLD.²⁴ There may have been some selection bias in the sample of midwives interviewed as they were self-selected through a poster campaign and were therefore more likely to have an interest in and motivation to improve the care of people with LD.²³

Recommendations

Training emerged consistently from the literature as a priority. Studies recommend midwives receive training and supervision for working with and providing services for WWLD. Additionally, clinical opportunities should be provided for working with WWLD alongside teaching support for student midwives.²³ Training for General Practitioners should include: assessment and diagnosis; knowledge of associated conditions; how to make reasonable adjustments; adapting communication; skills for physical examination in non-compliant patients; service coordination; and involving patients in decision making.^{21,23,24} In particular, making reasonable adjustments with respect to information giving, flexibility in services, consent, decision-making and assessment were highlighted. Homeyard *et al.* (2016) recommended reasonable adjustments should consider flexible and extended consultation times, communication aids, use of pictures, recording consultations, and flexibility in appointments with adequate time.¹² Jamieson *et al.* (2016) suggested women should be provided with information on the safeguarding process in advance.²⁰ This would reduce anxiety, stress and lessen surprise due to the unknown nature of the process of assessment.^{13,21}



Professionals need to work together. It is recommended that local gap analysis concerning training, guidance and resources is conducted and LD midwife forums are created to address these gaps.²³ Additionally, independent advocates have been proposed,

who can work as 'facilitators' between parents and professionals to improve engagement, promote professional practice and model positive attitudes.^{21,25}

In order to reduce fear and stigma around disclosing a pregnancy, Jamieson *et al.* (2016) recommend that services have proactive conversations with women about family planning.²¹ Further suggestions include support networks developed for pregnant WWLD and routine antenatal screening for negative emotional states.¹³

Conclusion

The existing research is limited in breadth and depth: there are few papers capturing experiences of WWLD during pregnancy, and previous research has mostly focussed on others' perspectives on the matter.¹⁹ Whilst this article provides a useful indicator of some of the issues WWLD may face during pregnancy, the paucity of the existing research limits transferability.

A number of issues were identified such as negative attitudes, lack of training and reasonable adjustments not being made. Easy read information was not being provided to women as standard, thus further increasing inequality faced by WWLD. Further qualitative research needs to be carried out across regions of the UK to encompass differences in antenatal services. In addition, a wider representation of ethnic groups should be included to further understand the experience of WWLD and to ensure saturation of themes are found. Quantitative research is then required to understand the prevalence of the issues and identify gaps regionally to put antenatal care support for WWLD into place.

Acknowledgments Thank you to Dr Guy Bradley Smith, University of Exeter, Exeter, UK, for facilitating the Learning Disabilities special study unit, for his support during the unit and feedback on my submitted essay.

Contribution statement The author has made substantial contributions to the conception of the work, drafted the article and gave the article final approval for inclusion in INSPIRE.

Copyright This work is licensed under the Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License. To view a copy of the license, visit <https://creativecommons.org/licenses/by-nc-nd/4.0/legalcode>. The copyright of all articles belongs to the author(s), and a citation should be made when any article is quoted, used or referred to in another work. All articles included in the INSPIRE Student Health Sciences Research Journal are written and reviewed by students, and the Editorial Board is composed of students. Thus, this journal has been created for educational purposes and all content is available for reuse by the authors in other formats, including peer-reviewed journals.

References

1. World Health Organization (2020). Definition: intellectual disability. Available from: www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/news/news/2010/15/childrens-right-to-family-life/definition-intellectual-disability. Accessed: 24 April 2020.
2. MENCAP (2020). What is a learning disability? Available from: www.mencap.org.uk/learning-disability-explained/what-learning-disability. Accessed: 24 April 2020.
3. World Health Organization (2018). ICD-11 for mortality and morbidity Statistics. Available from: <https://icd.who.int/browse11/l-m/en/http%3a%2f%2fid.who.int%2f%2fcd%2f%2f%2f1074941350>. Accessed: 24 April 2020.
4. Bhate S, Wilkinson S. Aetiology of learning disability. *Psychiatry*. 2006;5(9):298-301.
5. PHE (2018). Quality Outcomes Framework GP registration data. Learning Disability in England. Available from: <https://fingertips.phe.org.uk/>. Accessed: 24 April 2020.
6. Whitaker S. Hidden learning disability. *Br J Learn Disabil*. 2004;32(3):139-143.
7. Emerson E, Hatton C (2004). Estimating the current need/demand for supports for people with learning disabilities in England. Institute for Health Research, Lancaster University, Lancaster.
8. Emerson E, Hatton C, Felce D, et al (2001). Learning Disability the Fundamental Facts. Mental Health Foundation, London.
9. PEN (2015). Hidden voices of maternity parents with learning disabilities speak out. Available from: www.piccker.org/wp-content/uploads/2016/01/Hidden-Voices-of-Maternity-Report-FINAL.pdf. Accessed: 24 April 2020.
10. Chowdhury M, Benson BA. Deinstitutionalization and quality of life of individuals with intellectual disability: A review of the international literature. *J Policy Pract Intellect Disabil*. 2011;8(4):256-265. doi:10.1111/j.1741-1130.2011.00325.x
11. Hosking FJ, Carey IM, Shah SM, et al. Mortality among adults with intellectual disability in England: comparisons with the general population. *Am J Public Health*. 2016;106(8):1483-1490.
12. World Health Organization & United Nations Population Fund (2009). Promoting Sexual and Reproductive Health for Persons with Disabilities: WHO/UNFPA Guidance Note. World Health Organization, Geneva.
13. Homeyard C, Montgomery E, Chinn D, et al. Current evidence on antenatal care provision for women with intellectual disabilities: A systematic review. *Midwifery*. 2016;32:45-57.
14. O'Connor J (2011). Literature review on provision of appropriate and accessible support to people with an intellectual disability who are experiencing crisis pregnancy. Available from: www.lenus.ie/bitstream/handle/10147/122586/CPALitreview.pdf?sequence=1. Accessed: 24 April 2020.
15. McConnell D, Mayes R, Llewellyn G. Women with intellectual disability at risk of adverse pregnancy and birth outcomes. *J Intellect Disabil Res*. 2008;52(6):529-535.
16. Malouf R, McLeish J, Ryan S, et al. "We both just wanted to be normal parents": a qualitative study of the experience of maternity care for women with learning disability. *BMJ Open*. 2017;7(3):e015526.
17. Smith JA, Osborn M. Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. *Br J Pain*. 2015;9(1):41-42.
18. Redshaw M, Malouf R. Women with disability: the experience of maternity care during pregnancy, labour and birth and the postnatal period. *BMC Pregnancy and Childbirth*. 2013;13:174.
19. Höglund B, Larsson M. Struggling for motherhood with an intellectual disability—a qualitative study of women's experiences in Sweden. *Midwifery*. 2013;29(6):698-704.
20. Potvin L, Barnett B, Brown HK, et al. "I Didn't Need People's Negative Thoughts": Women With Intellectual and Developmental Disabilities Reporting Attitudes Toward Their Pregnancy. *Canadian Journal of Nursing Research*. 2019;51(3):154-167.
21. Jamieson R, Theodore K, Raczka R. Becoming a mother: Supported decision-making in context. *J Intellect Disabil*. 2016;20(4):313-328.
22. McConnell D, Llewellyn G. Stereotypes, parents with intellectual disability and child protection. *Journal of Social Welfare and Family Law*. 2002;24(3):297-317.
23. Castell E, Stenfort Kroese B. Midwives' experiences of caring for women with learning disabilities – A qualitative study. *Midwifery*. 2016;36:35-42.
24. Hemm C, Dagnan D, Meyer TD. Identifying training needs for mainstream healthcare professionals, to prepare them for working with individuals with intellectual disabilities: a systematic review. *J Appl Res Intellect Disabil*. 2015;28(2):98-110.
25. Tarleton B. Expanding the engagement model: The role of the specialist advocate in supporting parents with learning disabilities in child protection proceedings. *J Public Child Welf*. 2013;7(5):675-690.