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Women with learning disabilities

Date created: 29/05/2026

961111-027*

Maternity services for women with learning disabilities. (1996), MIDIRS Midwifery Digest vol 6, no 4, December 1996, p 400

A new steering group at the Maternity Alliance has been set up to look at maternity services for women with learning disabilities. Called Right from the Start, it would be interested to hear from anyone knowing of or involved in the midwifery care or parenthood teaching of women or parents with learning disabilities. It would be particularly valuable to hear about teaching aids or resources used in these circumstances, and whether they were useful. (Full text)

961103-010

Practical tips for supporting pregnant women with learning disabilities (1). Dixon K (1996), Disability, Pregnancy and Parenthood International no 16, October 1996, pp 8-9

In Britain women with identified learning disabilities usually attend school/college until they are 18 years of age. College courses often include some `sex education' and `family planning', presented in a very visual way, and these topics are often very discussion based. Many adults with learning disabilities who have left college, and can be funded to attend a day service have a degree of freedom to form relationships with other service users, although I would question the extent of such opportunities. These opportunities also depend on the severity of learning disability, and the level of support needed. Other clients with minimal support needs may have more freedom within the community. (Author)

961103-009

Right From The Start: maternity services for women with learning disabilities. Campion MJ (1996), Disability, Pregnancy and Parenthood International no 16, October 1996, pp 6-7

Right From The Start is a new 3 year project looking at ways of improving maternity service provision for people with learning disabilities. Launched by the Maternity Alliance, it is part-funded by Changing Childbirth, the government initiative to make woman-centred maternity services a reality for all women. Over the years there has been growing evidence that many women with learning disabilities do not have access to the same opportunities for choice, continuity and control which form the basis of good practice and yet they are women for whom all three are particularly critical. (Author)

961019-012*

Childbirth education for women with disabilities and their partners. Cheatham D, King E, Bartz A (1994), Columbus, Ohio: Ohio State University 1994. 231p

An A4, loose-leaf manual to give childbirth educators the information to support women with disabilities and their partners during pregnancy, specifically women with learning disabilities. It includes many good quality coloured illustrations and photocopiable handouts. Though few such resources are available, this manual would need many amendments for use in the UK. (Reviewed for MIDIRS by Bernadette Bryant, senor midwifery lecturer)

960903-038

Women with learning disabilities: the midwife's role. Minns HR (1996), In: Alexander J, Levy V, Roch S eds. Midwifery practice: core topics 1. Basingstoke: Macmillan Press Ltd 1996, pp 116-131

There is a wealth of information on childbirth and parenting for the woman with a physical disability but little for those with a learning disability. This chapter explores some of the issues, including sex education, the integration of people with learning disabilities into the community, preconception care and advice, antenatal care and preparation for parenthood, intrapartum care, and postnatal support. 42 references. (SJH)

960803-017

Right from the start. (1996), Maternity Action no 73, July-September 1996, p 3

The Maternity Alliance has set up a new project to investigate the provision of effective support for parents or prospective parents with a learning disability. (SJH)

960620-096*

Right from the start: maternity services for women with learning difficulties. Maternity Alliance (1996), London: Maternity Alliance 1 May 1996. 1 page

The Maternity Alliance is setting up a project to investigate what maternity service providers (midwives, health visitors, community nurses, social workers and voluntary agencies) are doing to provide effective support for parents and prospective parents who have learning difficulties. Those with relevant information, experiences and expertise are asked to contact the Maternity Alliance. (KL)

960319-001

Parents Together: support for parents with learning difficulties. Booth W (1996), Disability, Pregnancy and Parenthood International no 13, January 1996, p 13

A new research project based in Sheffield called Parents Together has begun to examine ways of delivering support to parents with learning difficulties. (Author)

950815-004*

Resource list: a parentability guide to pregnancy, birth and parenthood for people with disabilities. National Childbirth Trust (1995), London: National Childbirth Trust 1995. 84p

Resource list for disabled parents including listings of information services; practical help for parents; aids and equipment; link schemes and support groups; helplines and counselling services; published materials; TV, radio and video; campaigns, research and special projects; courses, seminars and conferences; rights and benefits; holidays and travel

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950215-008*

Pregnancy and parenthood for people with learning difficulties: what parents find helpful and unhelpful. ParentAbility (1994), London: National Childbirth Trust, ParentAbility February 1994. 14p

Report of a day to clarify how to make appropriate resources available for people with learning disabilities in pregnancy held at Highbury Roundhouse Centre on 29 November 1993. (KL)

950103-006*

Who's fit to be a parent?. Campion MJ (1995), London: Routledge 1995. 311p

Received for review.

941002-019

The right to choose. Cross G (1994), Nursing Times vol 90, no 39, 28 September-4 October 1994, pp 60-62

Gil Cross describes the care given to a woman with a learning disability who was determined to have a child of her own. (Author)

940803-088

Resources on pregnancy & parenthood for people with learning difficulties. O'Farrell J (1994), Disability, Pregnancy and Parenthood International no 5, January 1994, pp 11-13

A unique and important gathering took place recently in London - a day-long event to find ways to make available appropriate resources for people with learning difficulties in pregnancy and parenthood. The day was intended to be a positive recognition of parenting by people with learning difficulties, not simply a matter of addressing problems. (Author)

940424-039*

An aspect of health education for parents with special needs - a case report. Rose V (1993), Journal of the Institute of Health Education vol 31, no 3, 1993, pp 96-99

This project came about as a result of my work with a family with learning difficulties. The solution to some of their problems and special needs was a simple but effective visual aid. The aid was used to monitor the feeding of a premature, 'small for dates' baby following discharge from hospital. The mother was unable to read, write, tell the time, or count the number of ounces taken over a 24 hour period. The baby was failing to gain weight and it was necessary to teach the mother the feeding requirements and to determine how much milk was being taken at each feed. Liaison between the many professionals was assisted by the introduction of a communication card. The aid has been adopted to promote health education in four district health authorities. (Author)

940321-022

Health education for parents with special needs. Rose V (1994), Health Visitor vol 67, no 3, March 1994, pp 95-96

Working with families with communication and learning difficulties can require health visiting skills other than those taught on the formal health visitor training course, writes Val Rose. She describes how she approached the problems of one such family with a new-born baby, and the resulting design of a simple feed calculator and communication card which enabled parents and professionals to ensure the baby was being adequately nourished. (Author)

940306-026

Childbearing and parenting with a disability or chronic illness. Carty E, Conine T, Holbrook A, et al (1993), Midwifery Today no 28, 1993, pp 17-19, 40-42

No abstract available.

940303-014*

Learning to be mum. Campion MJ (1994), London: Arrowhead Productions on behalf of BBC Television 1994. 30 mins

Received for review.

940106-032

Assessment of fertility regulation in persons with a learning disability (mental handicap) - antecedents. Roy M, Corbett J, Newton J, et al (1993), Journal of Obstetrics and Gynaecology vol 13, no 6, November 1993, pp 473-480

The genesis and subsequent activities of the eugenic movement are reviewed. There developed a strong belief that the main causes of retardation were genetic and hence sterilisation and segregation were justified as a means of controlling the numbers of people with learning disabilities. More recent cases involving women with learning disabilities needing contraception are detailed to show the development of the concepts of consent and sexual rights of people with learning disabilities. Their rights to parenthood are contrasted with the rights of their parents and carers. It was concluded in order to protect the rights of people with a learning disability referred for sterilisation a clearer understanding was needed of the personal, familial and environmental processes that lead to such a referral. This could be done by comparing women referred for sterilisation with those using other forms of contraception. It would be useful to see how previous referrals had been assessed. Using the available information a comprehensive assessment procedure could be developed. (Author)

930604-068

Caregiving by mothers with mental retardation. Keltner BR (1992), Family and Community Health vol 15, no 2, 1992, pp 10-18

No abstract available.

930310-004

The right to procreate: intellectual disability and the law. Mair JLM (1992), Australian College of Midwives Incorporated Journal vol 5, no 4, December 1992, pp 16-20

The common law recognizes the right of every woman to bear a child and will not contravene that right unless there are compelling reasons for doing so. The issue of the right of intellectually disabled girls, below the age of 18 years, to ultimately bear a child has now been removed to the courts. Following a recent High Court decision, surgery resulting in the sterilisation of intellectually disabled minors cannot be performed without the sanction of the Family Court. Intellectually disabled women differ in that they are legally adults once they reach the age of majority with presumed full adult rights to consent to medical treatment. Other legal mechanisms are required when they lack this capacity. This article discusses the High Court case and others that have been heard in Australia recently. (Author)

920904-035

Mentally handicapped parents - some issues to consider in relation to pregnancy. Attard MT (1988), British Journal of Mental Subnormality vol 34, no 66, January 1988, pp 3-9

No abstract available.

920624-031

Reaching out to mothers with mental retardation. Keltner BR, Tymchuk AJ (1992), MCN - American Journal of Maternal/Child Nursing vol 17, no 3, May/June 1992, pp 136-140

As more and more mentally retarded women have children, nurses' one-on-one teaching and home care strategies are becoming crucial. (Author)

920608-039

The intensive mothercraft program - a report. Hanna C, Ebdell L (1992), Australian College of Midwives Incorporated Journal vol 5, no 1, March 1992, pp 25-27

A report on the Intensive Mothercraft Program (IMP) developed at The Queen Elizabeth Hospital (TEQH) Adelaide. This program was developed in 1987 mainly in response to needs demonstrated by parents, who were physically and/or intellectually disabled. (Author)

2026-05213

Exploring influences on infant-feeding decisions among mothers with learning disabilities: A scoping review. Mitchell V, McFadden A, Buell S (2026), Midwifery vol 156, May 2026, 104741

Background

During the transition to motherhood, women need to make decisions about infant-feeding. For women with learning disabilities, making such decisions is impacted by their capacity to interpret information. Understanding the influences on infant-feeding decisions can improve support for mothers with learning disabilities.

Aim

Our review explores broad intersecting influences, including autonomy, formal and informal support systems, and information delivery, by synthesising both peer-reviewed and grey literature. It aimed to understand these aspects in relation to infant-feeding decisions for mothers with learning disabilities and to identify evidence research gaps.

Methods

We conducted a scoping review following the Joanna Briggs Institute methods. Three electronic databases, Medline, CINAHL and PubMed were searched for peer-reviewed literature, and Google, Google Scholar and Ethos for grey literature in March 2023 and updated in March 2025. Articles were eligible for inclusion if the participants were mothers with learning disabilities and they included data on infant-feeding decisions. The peer-reviewed literature was analysed thematically, and the grey literature is summarised narratively

Findings

Six peer-reviewed papers and seven sources of grey literature were included. The findings suggested that mothers want autonomy regarding their infant-feeding decisions but are influenced by those around them, including family, friends, and professionals. Mothers can only make informed choices if timely information is tailored to the right level.

Conclusion

We found limited research on the influences on infant-feeding decisions for mothers with learning disabilities; more research is needed. Our review suggests that mothers with learning disabilities' infant-feeding decisions are influenced by their support networks. Effective accessible information on infant-feeding targeted to women with learning disabilities is needed. Maternity service policies should include guidance for supporting mothers with learning disabilities. (© 2026 The Authors. Published by Elsevier Ltd.)

Full URL: https://doi.org/10.1016/j.midw.2026.104741

2026-04546

Severe maternal morbidity and hypertensive disorders of pregnancy among women with intellectual disabilities: identifying potential intervention targets. Ryu RH, Psaras C, Baer R, et al (2026), American Journal of Obstetrics & Gynecology MFM 17 April 2026, online

Background

Women with intellectual disabilities experience higher rates of chronic health conditions and behavioral risk factors, yet the extent to which these factors contribute to adverse maternal outcomes is unclear.

Objective

To identify and prioritize intervention targets to reduce severe maternal morbidity and hypertensive disorders of pregnancy in women with intellectual disabilities.

Study Design

We conducted a population-based cohort study linking 2007-2020 California birth and fetal death records with hospital discharge, emergency department, and ambulatory surgery data. Among 6,099,797 singleton births, we created a 1:30 matched cohort of women with (n=1,114) and without ID, matched on age, birth year, race/ethnicity, payer type, participation in the Supplemental Nutrition Program for Women, Infants, and Children, and maternal nativity. Intellectual disability and outcomes were identified from International Classification of Diseases codes at delivery. We used generalized linear modeling to estimate risk differences, risk ratios, and respective 95% confidence intervals for the association between ID and adverse maternal outcomes including severe maternal morbidity, preeclampsia, and gestational hypertension. We performed regression-based joint and single mediation analyses to assess the contribution of selected mediators to the association between ID and these adverse maternal outcomes.

Results

Women without intellectual disabilities were younger [26.8 (SD=5.9) vs 29.0 (SD=6.2) years] and more likely to be non-Hispanic Black (19% vs 5%), have public payer for delivery (82% vs 48%), participate in nutrition assistance (79% vs 50%), and be born in the US (92% vs 80%). In the adjusted matched analytic sample, women with ID (n=1,107) were more likely to have inadequate prenatal care (40% vs 29%), substance use disorders during pregnancy (11-16% vs 3-6%) and mental health conditions (12-16% vs 2%) compared to women without ID (n=33,174). Additionally, women with ID were more likely to have chronic comorbidities including respiratory conditions (19% vs 6%), epilepsy (12% vs 1%), preexisting hypertension (7% vs 3%), preexisting diabetes (7% vs 1%), or hyperthyroidism or hypothyroidism (4% vs 1%).

Compared to women without intellectual disabilities, adjusted excess risk per 100 deliveries was 3.0 for severe maternal morbidity (95%CI: 1.8, 4.4), 7.8 for preeclampsia (95%CI: 5.8, 9.7), and 6.9 for gestational hypertension (95%CI: 4.8, 9.0). Corresponding adjusted risk ratio was 2.7 (95%CI: 2.1, 3.5) for severe maternal morbidity, 2.8 (95%CI: 2.3, 3.3) for preeclampsia, 2.0 (95%CI: 1.7, 2.3) for gestational hypertension.

Jointly, all mediators with sufficient frequencies explained 29.1% (95%CI: 15.9, 50.3) of the association between intellectual disability and severe maternal morbidity, 37.6% (95%CI: 27.6, 52.0) for preeclampsia, and 25.4% (95%CI: 5.8, 47.8) for gestational hypertension. In single-mediator analyses, epilepsy accounted for the greatest proportion of the total effect for severe maternal morbidity (11%), preexisting hypertension was the strongest mediator for preeclampsia (16%), and anxiety showed the highest proportion mediated for gestational hypertension (21%).

Conclusions

Chronic comorbidities and behavioral risk factors accounted for roughly one-quarter to one-third of the increased risks of severe maternal morbidity and hypertensive disorders of pregnancy in women with intellectual disabilities. These findings highlight opportunities for targeted preconception and prenatal interventions to improve maternal health equity. (© 2026 The Author(s). Published by Elsevier Inc.)

Full URL: https://doi.org/10.1016/j.ajogmf.2026.101968

2026-03741

Babies in care proceedings: What do we know about parents with learning disabilities or difficulties?. Burch K, Simpson A, Taylor V, et al (2024), Nuffield Family Justice Observatory, London, June 2024. 84 pages

This report explores the prevalence, circumstances and experiences of parents with learning disabilities or difficulties involved in care proceedings concerning their babies. It sets out key findings from an examination of court bundles, children's social care records and interviews with parents, lawyers and social care professionals in England. (© Nuffield Family Justice Observatory 2026)

Full URL: https://www.nuffieldfjo.org.uk/resource/babies-in-care-proceedings-what-do-we-know-about-parents-with-learning-disabilities-or-difficulties

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2026-03134

A lack of evidence for disability-inclusive maternal health interventions and promising progress: an updated systematic review. Dev A, Allen SE, Sisson S (2025), Frontiers in Global Women's Health 16 December 2025, online

Background:
Pregnant women with disabilities experience significantly higher rates of adverse pregnancy outcomes compared to those without disabilities. Evidence-based interventions that address disability-related barriers during pregnancy are essential to reducing health disparities.

Objective:
We aimed to update a 2014 systematic review to identify interventions designed for pregnant women with disabilities.

Methods:
We conducted a systematic review of studies published between 2012 and 2025 to identify interventions addressing disability-related barriers during pregnancy and birth.

Results:
We found a striking absence of evidence with no eligible studies identified from 22,719 publications. While we found multiple studies that evaluated the safety and efficacy of medications to manage disability-associated conditions during pregnancy, none of these studies focused on the potential disabling impact of the health conditions for pregnant women with disabilities, our intended focus. However, in our discussion, we describe three recent pilots, including co-produced resources for pregnant patients with disabilities, educational interventions for midwives, and an innovative patient empowerment tool, that suggest the field may be at a turning point.

Conclusions:
Our systematic review did not find evidence of disability inclusive maternal health interventions to improve pregnancy and childbirth experiences. However, we point to limited but promising studies for their use of co-production and patient engagement principles underscoring the potential for accelerating progress when research is conducted with, rather than on, disabled communities. While the pilots serve as proof of concept that disability-inclusive reproductive health research is both necessary and achievable, investments in disability inclusive maternal healthcare could yield significant returns for those with disabilities.

Full URL: https://doi.org/10.3389/fgwh.2025.1711871

2026-01624

Incidence and Outcomes of Surgically Managed Ectopic Pregnancy in Women With Disabilities: A Population-Based Cross-Sectional Study. Scime NV, Huang B, Brown HK, et al (2025), Paediatric and Perinatal Epidemiology 26 November 2025, online

Background
Disparities in the incidence, management, and outcomes of ectopic pregnancy have been documented among marginalised patients; however, there are few data on ectopic pregnancy in women with disabilities.

Objective
To compare the incidence and outcomes of surgically managed ectopic pregnancy in women with and without disability.

Methods
We conducted a population-based cross-sectional study using the National Inpatient Sample of discharges from US community hospitals (January 2016–December 2021). We analysed 9769 hospitalisations for surgically managed ectopic pregnancy among females aged 15–44 years. Disability was measured using a published administrative data diagnosis code algorithm. Outcomes were the incidence rate of ectopic pregnancy, surgical management approach (route, tubal removal versus sparing), complications (length of stay [LOS] ≥ 3 days, blood transfusion), and use of more extensive procedures than are standard (hysterectomy, oophorectomy, bilateral salpingectomy, tubal ligation). Weighted analyses were used to generate unadjusted incidence rate ratios (IRR) and outcome risk ratios (RR) from modified Poisson regression adjusted for year of surgery, socio-demographics, smoking, and comorbidities.

Results
The rate of surgically managed ectopic pregnancy was 2.8 per 1000 obstetric deliveries in disabled females and 2.3 per 1000 in non-disabled females (IRR 1.26, 95% CI 1.08, 1.45). Compared to non-disabled females, disabled females more often experienced prolonged LOS (adjusted RR 1.34, 95% CI 1.03, 1.74) and use of extensive procedures (adjusted RR 1.49, 95% CI 1.11, 2.00), including hysterectomy (adjusted RR 1.75, 95% CI 0.91, 3.36), oophorectomy (adjusted RR 1.43, 95% CI 0.96, 2.13), and bilateral salpingectomy (adjusted RR 1.30, 95% CI 0.71, 2.37); however, some estimates were imprecise due to low cell counts.

Conclusions
Disabled women faced slightly higher rates of surgically managed ectopic pregnancy and use of more extensive surgical procedures, including sterilisation. Targeted patient education on ectopic pregnancy and equity-focused guidance for surgeons may be beneficial.

Full URL: https://doi.org/10.1111/ppe.70089

2026-00791

Women with disabilities' experiences with respectful maternity care in Nepal: a phenomenological study. Noori S, Lanzarotti F, Herren L (2025), BMC Pregnancy and Childbirth vol 26, no 1, 25 November 2025, 3

Background
Respectful maternity care (RMC) is essential to safe, dignified childbirth, yet women with disabilities in Nepal face unique barriers in accessing such care. Limited evidence exists on their experiences in relation to the White Ribbon Alliance's RMC Charter.

Objective
To explore the lived experiences of women with disabilities regarding respectful maternity care in the semi-urban outskirts of Kathmandu, Nepal, and to identify priorities for improving maternity care.

Methods
A phenomenological study design was employed between April and May 2023. Data collection included 12 in-depth interviews with women with disabilities, 7 with healthcare providers, and 2 focus group discussions with 11 Female Community Health Volunteers. Interviews were audio-recorded, transcribed, translated into English, and thematically analyzed, guided by the RMC Charter.

Results
Women's experiences varied widely. Negative accounts included disrespect, poor communication, compromised privacy, and structural barriers such as overcrowded facilities and lack of disability-friendly infrastructure. Economic constraints and transport challenges further limited timely access to care. Some providers perceived women with disabilities as having limited autonomy, though most women reported making their own healthcare decisions. Positive experiences included respectful communication, practical support, and personal assistance from providers.

Conclusion
Women with disabilities in the Kathmandu outskirts encounter disability-specific barriers to respectful maternity care, including provider attitudes, inadequate communication, and inaccessible facilities. We recommend integrating disability-focused RMC training into health professional curricula, investing in disability-friendly infrastructure, and adopting policies that safeguard privacy, dignity, and autonomy.

Full URL: https://doi.org/10.1186/s12884-025-08398-y

2026-00207

Development of Quality Indicators for Pregnancy Care of People With Disabilities Using a RAND-Modified Delphi Method. Liu KJ, Pituch E, Barrett K, et al (2025), JOGC [Journal of Obstetrics and Gynaecology Canada] vol 47, no 11, November 2025, 103106

Objectives
This study aimed to develop quality indicators (QIs) for pregnancy care of people with disabilities.
Methods
We used a RAND-modified Delphi method. We first conducted a scoping review of Medline, Embase, PsycInfo, and CINAHL (2004–2024) to identify candidate QIs related to the structures, clinical processes, and interpersonal processes of pregnancy care for people with disabilities. Draft QIs were then validated in a 3-round Delphi study from June 2023 to October 2024, with an expert panel of 17 pregnancy care providers and 10 birthing people with disabilities. In round 1, panellists rated draft QIs on importance and feasibility in a survey. New QIs and QIs requiring rephrasing were identified. In round 2, QIs were discussed and refined in focus groups. In round 3, panellists rated new and revised QIs on importance and feasibility. The final list of QIs was created on the basis of panel consensus on importance.
Results
The review identified 98 studies, from which 44 candidate QIs were created for structures (n = 12), clinical processes (n = 22), and interpersonal processes of care (n = 10). In round 1 of the Delphi survey, consensus on importance was achieved for all QIs, 5 of which were identified as requiring rephrasing. Panellists suggested 10 new QIs. In round 2, the new and revised QIs were discussed in focus groups. In round 3, the new and revised QIs achieved consensus on importance, resulting in a final list of 54 QIs (n = 43 achieving consensus on feasibility).
Conclusions
These QIs can assist health care providers, administrators, and policymakers in optimising the quality of pregnancy care for people with disabilities. (© 2025 The Author. Published by Elsevier Inc. on behalf of The Society of Obstetricians and Gynaecologists of Canada/La Société des obstétriciens et gynécologues du Canada.)

Full URL: https://doi.org/10.1016/j.jogc.2025.103106

2025-15087

Receipt of Screening, Services, and Counseling During Perinatal Health Care Visits by Disability Status in the United States, 2018–2020. Deierlein AL, Boege HL, Berube LT, et al (2025), Obstetrics & Gynecology 25 November 2025, online

OBJECTIVE:
To examine the receipt of screening, services, and counseling during prepregnancy reproductive health, prenatal care, and postpartum care visits by disability status among people with recent live births in the United States.

METHODS:
Cross-sectional data were from 24 states in PRAMS (Pregnancy Risk Assessment Monitoring System) that included the WGSS (Washington Group Short Set of Questions) on Disability (October 2018–December 2020). Participants reported receipt of screening, services, and counseling during prepregnancy reproductive health care visits, prenatal care visits, and a postpartum checkup at 4–6 weeks postdelivery. Associations between the extent of disability (some and a lot of difficulty vs none) and components of health care visits were estimated using modified Poisson regression, adjusted for sociodemographic characteristics (adjusted prevalence ratios [aPRs] and 95% CIs).

RESULTS:
A total of 41,027 participants were included in analyses; 33.7% (n=14,047) reported having some difficulty and 6.2% (n=2,714) reported having a lot of difficulty. Differences were observed for screening, services, and counseling received at health care visits by disability status. During prepregnancy reproductive health care visits, people with any difficulty reported similar receipt of care as those with no difficulty, with the exception of a lower prevalence of discussions about improving their health (aPR 0.92; 95% CI, 0.86–0.98) and sexually transmitted infections (aPR 0.89; 95% CI, 0.83–0.95). During prenatal and postpartum visits, people with any difficulty had a lower prevalence of discussions about lifestyle behaviors, pregnancy weight gain and weight loss, interpersonal violence, mental health, breastfeeding, and birth control, as well as being tested for diabetes (aPR ranged from 0.72–0.99).

CONCLUSION:
Perinatal health care visits provide opportunities to improve health and assist in the transition to parenthood. Our findings highlight the need for strategies to reduce barriers to care for people with disabilities and facilitate effective communication during visits. (© 2025 by the American College of Obstetricians)

Full URL: https://doi.org/10.1097/AOG.0000000000006133

2025-14763

Adverse outcomes during delivery hospitalizations among patients with an intellectual or developmental disability diagnosis. Rao MG, Wen T, D'Alton M, et al (2025), American Journal of Obstetrics & Gynecology (AJOG) vol 233, no 6, December 2025, pp e230-e231

The objectives of this analysis were to determine trends in delivery hospitalizations with an IDD diagnosis and evaluate whether IDD is associated with adverse obstetric outcomes in a large national sample. (© 2025 Published by Elsevier Inc.)

2025-13212

A Qualitative Study on Breastfeeding among Mothers with Intellectual Disabilities: Perspectives of Nurse-Midwives and Public Health Nurses. Sugiura K, Fujisawa K (2022), Women, Midwives and Midwifery vol 2, no 3, October 2022, pp 28-40

Background: Breastfeeding is important for maintaining and promoting lifelong health and bonding between mother and child. Professional support in the early postpartum period is key to successful breastfeeding. Mothers usually learn parenting skills in the early postpartum period, but mothers with intellectual disabilities (IDs) require special consideration due to their low learning ability. The views of midwives and public health nurses regarding breastfeeding support for mothers with intellectual disabilities in the early postpartum period need to be clarified.

Purpose: The study aimed to describe the perspectives of nurse-midwives (NMWs) and public health nurses (PHNs) on breastfeeding for mothers with intellectual disabilities.

Methods: Data obtained from semi-structured interviews with five NMWs and five PHNs with experience in caring for postpartum mothers with IDs were analysed using a conventional content analysis approach.

Results: The analysis yielded two categories ‘Determining whether breastfeeding is the best’ for NMWs and ‘Desire for strengthened support for establishing breastfeeding during postpartum hospitalization’ for PHNs. The former comprised three subcategories: ‘Effects of complications and abnormal deliveries’, ‘Evaluation of adaptability’, and ‘Evaluation of support person's capability’, while the latter consisted of ‘Focus on the advantages of breastfeeding’, ‘Focus on the disadvantages of artificial breastfeeding’, and ‘Desire for NMWs’ support during postpartum hospitalization to establish breastfeeding’. It was established that NMWs had short-term perspectives that considered the physical trauma and fatigue sustained by mothers during childbirth and they tried to minimize their physical and emotional burden, whereas PHNs had long-term perspectives that considered the impact of breastfeeding on children’s future.

Conclusion: Successful breastfeeding by mothers with IDs requires a change in NMWs’ awareness and the development of a system and instructional media that enable NMWs to perform their responsibilities in accordance with the basic principles of breastfeeding. Additionally, policies are required to promote this practice. (© by Authors.Some rights reserved.)

Full URL: https://wmmjournal.org/index.php/wmm/article/view/69

2025-12167

Patient Disability Status and the Use of Stigmatizing Language in Clinical Notes During Hospital Admission for Birth. Harkins SE, Hulchafo II, Scroggins JK, et al (2025), JOGNN: Journal of Obstetric, Gynecologic and Neonatal Nursing vol 54, no 6, November 2025, pp 606-617.e3

Objective
To examine the association between patient disability status and use of stigmatizing language in clinical notes from the hospital admission for birth.
Design
Cross-sectional study of electronic health record data.
Setting
Two urban hospitals in the northeastern United States.
Participants
Patients at more than 20 weeks gestation admitted for birth from 2017 to 2019 (N = 19,094).
Methods
We used a natural language processing algorithm to identify categories of stigmatizing language used in free-text clinical notes (N = 211,841 unique clinical notes). We employed multivariable logistic regression to estimate adjusted odds ratios (aORs) and 95% confidence intervals (CIs) for each stigmatizing language category by disability status, which we determined by ICD-10 (International Classification of Diseases, 10th revision) codes.
Results
Approximately 3% of patient records (n = 550) included ICD-10 codes for disability. Clinicians were more likely to use stigmatizing language for patients with disabilities compared with patients without disabilities (aOR = 1.75, 95% CI = [1.47, 2.09]). For patients with disabilities compared with patients without disabilities, clinicians were also more likely to use stigmatizing language in the difficult patient category (aOR = 1.96, 95% CI = [1.65, 2.33]) and the unilateral/authoritarian decisions category (aOR = 1.27, 95% CI = [1.06, 1.53]). We found no significant differences for the marginalized language/identities category by patient disability status (aOR = 1.19, 95% CI = [0.87, 1.62]).
Conclusion
The use of stigmatizing language in birth hospitalization notes differed by patient disability status. Stigmatizing language should be used as a marker of bias and an opportunity for clinicians to reflect on their thoughts, words, and actions. Patient-centered documentation and care practices are needed to improve perinatal health for all.

2025-11348

Maternal outcomes among women with intellectual disabilities in comparison with the general population (IDcare). Axmon A, Liu C, Grotta A, et al (2025), AJOG Global Reports vol 5, no 4, November 2025, 100569

Background

Women with intellectual disabilities face significant barriers to gynecological, reproductive, antenatal, and perinatal care, which may adversely impact maternal and fetal health. Previous research indicates increased risks for gestational diabetes, pre-eclampsia, caesarean birth, preterm birth, and other complications in pregnant women with intellectual disabilities. However, studies on the reproductive health in this group remain scant, and comprehensive research on maternal and fetal health from pregnancy to the postpartum period remain missing.

Objective(s)

Using high-quality data from Swedish registers, the present study aims to examine a full range of maternal and fetal outcomes among birthing women with intellectual disabilities and to compare them to those of birthing women in the general population. Such knowledge is important in understanding and preventing adverse health outcomes.

Study Design

This was a register study based on all women living in Skåne, Sweden on January 1st, 2104, with at least 1 singleton birth in 2014–2021. By linking regional and national registers, we were able to compare maternal and fetal outcomes in a cohort of women with intellectual disabilities (n=378), including a subgroup of women with diagnosis of mild intellectual disability (n=177), to outcomes among women from the general population (n=65 925). Diagnoses (i.e., outcomes) were collected from the Skåne Healthcare Register, which comprises all healthcare contacts in the Skåne region in Sweden. Poisson regression was used to estimate relative risks (RRs) with 95% confidence intervals (CIs) to quantify the association between intellectual disability and each outcome. The fully adjusted model included maternal year of birth and age at birthing, sociodemographic indicators, and obstetric comorbidities.

Results

In the fully adjusted models, women with intellectual disabilities had increased risk of pre-eclampsia (RR 1.67, 95% CI 1.15–2.42), infections of the genitourinary tract (2.30, 1.67–3.16), premature rupture of membranes (2.42, 1.24–4.69 for women with mild intellectual disability), and false labor (1.27, 1.05–1.53). In crude (i.e., unadjusted) models, increased risks were also found for maternal care for known or suspected fetal abnormality and damage, maternal care for other known or suspected fetal problems, other disorders of amniotic fluid and membranes, antepartum hemorrhage, not elsewhere classified, and failed induction of labor.

Conclusion(s)

Pregnant women with intellectual disabilities have increased risk of several adverse maternal outcomes, with the risk for some likely driven-at least in part-by lower sociodemographic status and worse obstetric health. (© 2025 The Authors. Published by Elsevier Inc.)

Full URL: https://doi.org/10.1016/j.xagr.2025.100569

2025-11031

“I feel like I'm not confident enough”: A qualitative study of Cambodian midwives’ experiences in disability-inclusive maternity care. Ven C, Marella M, Vaughan C, et al (2025), Midwifery vol 148, September 2025, 104472

Objective

Midwives often experience challenges in meeting the maternity care needs of women with disabilities. Understanding context-specific factors influencing their experiences is essential if these challenges are to be addressed. This study aims to explore the experiences of Cambodian midwives regarding the provision of maternity care services for women with disabilities in Cambodia. In so doing, this study seeks to understand the barriers and facilitators that midwives encounter when delivering services to women with disabilities.

Research design

Drawing on the World Health Organization Quality of Care framework, this qualitative study employed a phenomenological design. Purposive sampling was used to recruit fifteen midwives across the diverse geographical settings of Phnom Penh, Kampong Speu and Kampot. Participants engaged in an in-depth semi-structured interview. All interviews were audio recorded, transcribed verbatim, and thematically analysed.

Results

Most participants reported past experiences in which they had provided maternity care to women with disabilities and professed their strong commitment to continue doing so. Key challenges undermining the capabilities, confidence, and therefore commitment of the midwives to providing this care included the lack of evidence-based guidelines and training on caring for women with disabilities, including communication challenges, insufficient mechanisms for identifying women with disabilities and their care needs, and inadequate referral systems and processes to respond to emergencies. These midwives also highlighted challenges they faced in supporting women to link into other key services such as social services, rehabilitation, and mental health services. Midwives were eager to receive more training and resources to strengthen their capacity to adequately meet the maternity care needs of women with disabilities.

Conclusion

Cambodian midwives have identified several barriers to delivering disability-inclusive maternity care. To address these challenges, it is crucial to incorporate disability training into both pre-service and in-service training programs. Establishing evidence-based guidelines for disability-inclusive maternity care, ensuring essential physical resources, and developing accessible and reliable functional referral systems are priorities. Furthermore, midwives would benefit from receiving training in communicating with women with diverse disabilities and in collecting and assessing data on disability-related care needs when women with disabilities access maternity care services.

Statement of Significance

Globally, women with disabilities encounter substantial socio-economic and health disparities, which are further exacerbated by systemic barriers in accessing essential health services. This is particularly evident in maternity care, where women with disabilities often encounter obstacles such as inaccessible facilities, a lack of awareness about disabilities among healthcare providers, discriminatory attitudes, communication barriers, and limited financial resources to access the necessary care. Although healthcare providers have cited providing maternity care services to women with disabilities as a rewarding experience, several barriers hinder their ability to provide maternity care services with disability inclusion. Numerous global studies have identified the challenges faced by healthcare providers in providing maternity services to this population, including insufficient disability training, a lack of evidence-based guidelines, a lack of functional referral systems, and limited essential physical resources. However, there remains a limited understanding of context-specific factors influencing healthcare providers’ capability and experiences, which impedes efforts to support healthcare providers, particularly in resource-constrained settings in low- and middle-income countries such as Cambodia. This knowledge gap negatively impacts the capacity of healthcare providers in offering disability-inclusive care and contributes to ongoing disparities in maternity care outcomes for women with disabilities. Therefore, this study aims to explore the experiences of Cambodian midwives regarding the provision of maternity care services for women with disabilities in Cambodia. In so doing, this study seeks to understand the barriers and facilitators that midwives encounter when delivering services to women with disabilities. This study provides empirical evidence about the challenges and facilitators faced by Cambodian midwives in delivering maternity care services to women with disabilities in a resource-constrained setting. The findings contribute to the existing body of knowledge related to maternity care for women with diverse types of disabilities, which could be used to inform policy, planning, practice, and strategies to improve disability-inclusive maternity care in Cambodia and other countries with similar contexts.

Full URL: https://doi.org/10.1016/j.midw.2025.104472

2025-08238

Voice of a... Midwifery clinical research manager. Ambler S-J (2025), Midwives vol 28, April 2025, p 17

Sarah-Jayne Ambler at Medway NHS Foundation Trust was involved in a pilot of resources to improve maternity care for parents with learning disabilities. (© Author)

2025-07306

Identifying Pregnant Women With Disabilities and Maternal and Newborn Outcomes. Dev A, Horner-Johnson W, Schaefer A (2025), JAMA Network Open vol 8, no 3, March 2025,e252159

Importance Pregnant women with disabilities are at higher risk of poor pregnancy and birth outcomes. Different methods for identifying disability may affect estimates of health disparities in this population.

Objective To compare pregnancy and birth outcomes among pregnant women using different ways of identifying maternal disability.

Design, Setting, and Participants Retrospective cohort study of linked vital records and maternal and newborn claims for Medicaid-insured live births from January 2010 to December 2014 in Texas. Data analysis was conducted from October 2023 to May 2024.

Exposure Births grouped into 5 maternal cohorts: no identified disability, disability benefits enrollment only, disability diagnostic code only, both benefits enrollment and a diagnostic code, and either disability benefits or a diagnostic code.

Main Outcomes and Measures Mode of delivery (cesarean) and severe maternal morbidity (SMM) were identified from maternal claims. Low birthweight (LBW), preterm birth (PTB), and small for gestational age (SGA) were identified from birth certificates. Modified Poisson regression with robust variance estimators was used to estimate adjusted risk ratios (aRRs) for the association of each of the 5 outcomes with disability group status.

Results Among 921 218 births (mean [SD] maternal age at birth, 25.1 [5.7] years), 895 201 (97.2%) were to mothers with no disability, 6160 (0.7%) were to mothers enrolled in disability benefits only, 17 742 (1.9%) were to mothers with a disability diagnostic code only, 2115 (0.2%) were to mothers with both benefits enrollment and a disability code, and 26 017 (2.8%) were to mothers meeting either disability definition. Compared with those without disabilities, those with only disability diagnostic codes had the highest rates for cesarean delivery (306 589 births [34.3%] vs 7658 births [43.2%]), LBW (750 058 births [8.4%] vs 869 births [14.2%]), and PTB (92 807 births [10.4%] vs 977 births [15.9%]). Compared with those with no disability, the adjusted relative risks were highest in the diagnostic codes only group for cesarean delivery (aRR, 1.22; 95% CI, 1.20-1.24), LBW (aRR, 1.77, 95% CI, 1.71-1.84), and PTB (aRR, 1.68; 95% CI, 1.62-1.74). The risk for SMM (aRR, 4.82; 95% CI, 3.96-5.86) and SGA (aRR, 1.43; 95% CI, 1.24-1.66) were highest in those with both benefits enrollment and a disability code.

Conclusions and relevance In this cohort study, disability was associated with adverse outcomes, regardless of definition. However, the burden of disparities was dependent on how disability was defined, suggesting that the assessment of disability-associated health risks should consider how disability is conceptualized. (©Author)

Full URL: https://doi.org/doi:10.1001/jamanetworkopen.2025.2159

2025-07137

Maternal Disability and Emergency Department Use for Infants. Brown HK, Lunsky Y, Fung K, et al (2025), JAMA Network Open vol 8, no 5, May 2025, e258549

Importance Infants have among the highest rates of emergency department (ED) visits of all age groups. Women with disabilities experience significant social disparities, may experience barriers accessing child primary care, and may seek care in the ED.

Objective To compare ED use among newborns and infants (hereafter infants) of women with or without disabilities, overall and by timing and acuity of the ED visit.

Design, Setting, and Participants This population-based cohort study analyzed data for all live-born infants in Ontario, Canada, born to women with or without a disability from April 1, 2008, to March 31, 2021. Data were analyzed March 2023 to October 2024.

Exposure Maternal physical, sensory, or intellectual or developmental disability or multiple disabilities status was ascertained using diagnostic algorithms applied to health care encounters before delivery.

Main Outcomes and Measures The main outcome was any ED visit between an infant's hospitalization discharge date and their first birthday, and by timing and acuity. Cox proportional hazards regression was used to generate hazard ratios (HRs) for the association between maternal disability and the main outcome, adjusted for sociodemographic characteristics and infant sex and year of birth.

Results Of 1 596 932 total infants, there were 139 698 (8.7%) born to women with a physical disability, 48 112 (3.0%) to women with a sensory disability, 2547 (0.2%) to women with an intellectual or developmental disability, and 10 312 (0.6%) to women with multiple disabilities. The remaining 1 396 263 infants (87.4%) were born to a woman without a recognized disability. Among women without a disability, 558 965 infants (40.0%) had an ED visit in the first year of life (incidence rate, 1.11 per 1000 person-days). Compared with this referent group, infants born to a woman with a disability of a physical (46.9%; 1.30 visits per 1000 person-days; adjusted HR [AHR], 1.14 [95% CI, 1.13-1.15]), sensory (45.2%; 1.25 visits per 1000 person-days; AHR, 1.09 [95% CI, 1.07-1.10]), or intellectual or developmental (55.4%; 1.55 visits per 1000 person-days; AHR, 1.24 [95% CI, 1.17-1.30]) nature or with multiple disabilities (51.0%; 1.42 visits per 1000 person-days; AHR, 1.18 [95% CI, 1.15-1.22]) were more likely to have an ED visit. Similar patterns were observed for ED visits at fewer than 28 days from delivery, from 28 to 365 days, and for ED visits for high-acuity, moderate-acuity, and low-acuity reasons.

Conclusions and Relevance In this population-based cohort study, infants of women with disabilities were more likely to use the ED, indicating a need for accessible family supports and improved early child primary care access. (© 2025 Brown HK et al.)

Full URL: https://doi.org/10.1001/jamanetworkopen.2025.8549

2025-06671

Development Aid: Sexual and Reproductive Health [written answer]. House of Commons (2025), Hansard Written question 57021, 3 June 2025

To ask the Secretary of State for Foreign, Commonwealth and Development Affairs, whether he will continue to provide funding to (a) the Women's Integrated Sexual Health program, (b) other Sexual and Reproductive Health and Rights programs and (c) access to those programs for (i) people with disabilities and (ii) other marginalised groups. (© UK Parliament 2025)

Full URL: https://questions-statements.parliament.uk/written-questions/detail/2025-06-03/57021

2025-06197

What to expect from mandatory training. Evans E (2023), Nursing Standard vol 38, no 2, 1 February 2023, p 13

Issues the new programme covers and who will undertake each tier,

All health and care staff in England are receiving training on supporting people with learning disabilities and autistic people. (© Author)

2025-06064

Access to Obstetric and Gynecologic Care for Patients With Disabilities ACOG Committee Statement No. 18. American College of Obstetricians and Gynecologists (2025), Obsterics & Gynecology vol e145, no 5, May 2025, pp 553-563

Although the Americans with Disabilities Act has been the law for more than 30 years, individuals with disabilities still face substantial barriers to health care and are at higher risk of receiving inadequate care than those without disabilities. It is important that obstetrician–gynecologists are aware of best practices for caring for their patients with disabilities, as well as how to adjust their offices, workflows, and practice patterns to be inclusive of all patients. Obstetrician–gynecologists and other reproductive health care professionals should understand the barriers that prevent disabled people from accessing reproductive health care. This is critical in identifying inequities and informing patient-centered approaches to services. Patients with disabilities should have access to the same health care as all patients, including all age-appropriate screening tests. It is important that health care teams acknowledge their inherent biases and offer and facilitate access to appropriate care, including recommended screening tests. Increasing training and exposure to individuals with different disabilities during medical training programs will not only help improve the lack of experience, but also help challenge the implicit and explicit biases that currently exist in health care. (© Author)

Full URL: https://doi.org/10.1097/AOG.0000000000005879

2025-03741

Factors influencing the capacity of healthcare providers to deliver disability-inclusive maternity care services: A scoping review. Ven C, Marella M, Vaughan C, et al (2025), Midwifery vol 143, April 2025, 104321

Objective

Current evidence highlights that women with disabilities experience challenges in accessing maternity care. Improving access requires an understanding of the factors influencing the capacity of healthcare providers to provide disability-inclusive care. Although providing maternity care services for women with disabilities has been reported to be a rewarding experience, numerous factors may impact health care providers' capacity to do so. Limited evidence, especially from low and middle-income countries (LMICs), undermines our understanding of this issue and how to respond. This scoping review, therefore, aims to synthesise the current published literature examining factors influencing the capacity of healthcare providers to deliver disability-inclusive maternity care services.

Design

This scoping review used the Arksey and O'Malley framework in accordance with the PRISMA extension for Scoping Reviews. A systemic search of six electronic databases, including MEDLINE (Ovid), CINAHL Complete, Scopus, Eric Ebsco, Web of Science Core Collection, and EMBASE (Ovid), was undertaken to identify relevant studies. Snowball searching of reference lists and citations was also performed. The Quality of Care Framework for Maternal and Newborn Health, developed by the World Health Organization, was employed to guide the analysis and synthesis of the findings of this review.

Findings

Twenty-four studies published between 2000 and 2023 met the inclusion criteria. Factors influencing the capacity of healthcare providers to provide disability-inclusive maternity care were identified and categorised into six domains aligning with the Quality of Care framework: 1) Evidence-based practices for routine care and management of complications; 2) Actionable information systems; 3) Effective communication; 4) Respect and dignity; 5) Competent and motivated human resources; and 6) Essential physical resources available.

Key conclusions and implications for practice

This scoping review synthesised evidence on six key factors affecting the capacity of healthcare providers to provide disability-inclusive maternity care. It highlights the need to address the limited application of a 'disability lens' to evidence-based guidelines and health information. The review also highlights the need to better enable healthcare providers at all stages of their training and clinical practice to develop their knowledge and skills in providing respectful, disability-inclusive maternity care, in addition to ensuring essential physical resources are available. Very few studies examine the capacity of healthcare providers in low- and middle-income countries. Future research should focus on developing context-specific evidence from such countries, particularly given that this is where the majority of women with disabilities live. (Author)

Full URL: https://doi.org/10.1016/j.midw.2025.104321

2025-01752

Pregnancy and postnatal outcomes for women with intellectual disability and their infants: A systematic review. Lo HWJ, Poston L, Wilson CA, et al (2025), Midwifery vol 142, March 2025, 104298

Background

While the perinatal period is a vulnerable time for women and their infants, it is also a window to promote adjustment and support. Women with intellectual disability might be a uniquely vulnerable group owing to pre-existing health and care inequalities. The aim of this paper is to explore the pregnancy and postnatal outcomes of women with intellectual disability and the health and development of their infants.

Methods

Three electronic databases (MEDLINE, PsycINFO, EMBASE) were searched for peer-reviewed papers that reported maternal pregnancy variables and infant outcomes within the first 12 months of life. Two reviewers screened 103 full text articles, of which nine met eligibility criteria. Data reporting maternal health, pregnancy complications, labour variables, and birth and neonatal outcomes were extracted, and findings were summarised narratively.

Findings

Women with intellectual disability were at an overall higher risk of adverse obstetric and pregnancy outcomes, such as urinary tract infection, gestational hypertension, and postpartum haemorrhage. Similarly, infants of women with intellectual disability had higher rates of premature birth, perinatal mortality, and experienced longer hospital stays when compared to their counterparts born to women without intellectual disability.

Conclusions

The relative sparsity of literature in this field demonstrates the need for further focused study on the pregnancy and postnatal outcomes of women with intellectual disability and their infants. Nonetheless, findings indicate that maternity services need to be further developed to provide optimum care for women with intellectual disability and to support infant development. (Author)

Full URL: https://doi.org/10.1016/j.midw.2025.104298

2025-00673

Disability justice and collective access to labour and delivery care: a qualitative study. Evans M, Tarasoff LA, Lunsky Y, et al (2024), BMC Pregnancy and Childbirth vol 24, no 832, December 2024

Background

People with disabilities experience perinatal health disparities. This qualitative study examines disabled people’s experiences of labour and delivery care from a disability justice lens.

Methods

Semi-structured interviews were conducted between July 2019 and February 2020 with 31 women and transgender people aged 18–45 years with physical, sensory, and/or intellectual/developmental disabilities, who were living in in Ontario, Canada and had given birth in the previous five years.

Results

People with disabilities described negative experiences of provider-driven, disrespectful, and discriminatory labour and delivery care that can be interpreted as examples of disability injustice and obstetric ableism. People with disabilities also described positive experiences of collaborative, respectful, and disability-affirming labour and delivery care that can be interpreted as examples of disability justice, facilitated by what feminist disability justice scholars and activists call collective access.

Conclusions

Collective access to labour and delivery care can improve perinatal health care for people with disabilities and promote disability justice. Reimagining care-related decision-making as an interdependent, collaborative, respectful, and disability-affirming process shared between patients and providers can help to facilitate collective access to labour and delivery care. (Author)

Full URL: https://doi.org/10.1186/s12884-024-07036-3

2024-12418

Cognitive impairment and the associated factors among women with a history of pregnancy complications in rural southwestern Uganda. Kihumuro RB, Kellen P, Chun S, et al (2023), PLoS ONE vol 18, no 10, October 2023, e0293258

Background
Worldwide, there is a growing concern about the rising number of people with declining cognitive functioning. However, findings on this phenomenon are inconclusive. Our study aimed to assess the prevalence of cognitive impairment and the associated factors in women with a history of pregnancy complications in rural southwestern Uganda.

Methods
This was a cross-sectional study carried out among women above 40 years of age in the greater Kabale district of southwestern Uganda between March and April 2022. Study participants were identified using a consecutive sampling method. Predictor variables included pregnancy complications and other social demographic factors that were assessed by semi-structured interviews while cognitive functioning as an outcome variable was assessed by Montreal Cognitive Assessment (MoCA-B) tool. Data were analyzed using STATA at a 95% Confidence level. Logistic regression analyses were selected for statistical modelling while odds ratios were calculated to assess the strength of associations between the predictor and outcome variables.

Results
In total, 75% (212/280) of participants had some form of cognitive impairment, with 45% (123/280) falling into mild CI, 31% (86/280) moderate CI and 4% (10/280) severe CI. Twenty-three percent (68/280) of participants fell into category of normal cognitive functioning. Participants with >65 years of age had higher odds of developing cognitive impairment (OR = 2.94; 95%CI: 0.96–9.04, p = 0.06) than those with < 65 years of age. Protective factors to cognitive impairment include delivering from a health facility (OR = 0.31,95% CI:0.16–0.60, p = < .001), primary and post primary levels of education (OR = 0.05; 95% CI: 0.02–0.13, p<0.001, OR = 0.04; 95%CI: 0.02–0.23, p<0.001) respectively.

Conclusion
Results from this study show a high prevalence of cognitive impairment among women with a history of pregnancy complications in rural southwestern Uganda. Interventions geared toward preventing cognitive impairment among females with a history of pregnancy complications should be emphasized. (Author)

Full URL: https://doi.org/10.1371/journal.pone.0293258

2024-10808

Perinatal and Postpartum Health Among People With Intellectual and Developmental Disabilities. Shea L, Sadowsky M, Tao S, et al (2024), JAMA Network Open vol 7, no 8, August 2024, e2428067

Importance Small, geographically limited studies report that people with intellectual and developmental disabilities (IDD) have increased risk for serious pregnancy-related and birth-related challenges, including preeclampsia, preterm birth, and increased anxiety and depression, than their peers. United States–based population-level data among people with IDD are lacking.

Objectives To identify perinatal and postpartum outcomes among a national, longitudinal sample of people with IDD enrolled in public health insurance, compare subgroups of people with IDD, and compare outcomes among people with IDD with those of peers without IDD.

Design, Setting, and Participants This retrospective cohort study used national Medicaid claims from January 1, 2008, to December 31, 2019, for 55 440 birthing people with IDD and a random sample of 438 557 birthing people without IDD. Medicaid funds almost half of all births and is the largest behavioral health insurer in the US, covering a robust array of services for people with IDD. Statistical analysis was performed from July 2023 to June 2024.

Exposure People who had a documented birth in Medicaid during the study years.

Main Outcome and Measures Perinatal outcomes were compared across groups using univariate and multivariate logistic regression. The probability of postpartum anxiety and depression was estimated using Kaplan-Meier and Cox proportional hazards regression.

Results The study sample included 55 440 birthing people with IDD (including 41 854 with intellectual disabilities [ID] and 13 586 with autism; mean [SD] age at first delivery, 24.9 [6.7] years) and a random sample of 438 557 birthing people without IDD (mean [SD] age at first delivery, 26.4 [6.3] years). People with IDD were younger at first observed delivery, had a lower prevalence of live births (66.6% vs 76.7%), and higher rates of obstetric conditions (gestational diabetes, 10.3% vs 9.9%; gestational hypertension, 8.7% vs 6.1%; preeclampsia, 6.1% vs 4.4%) and co-occurring physical conditions (heart failure, 1.4% vs 0.4%; hyperlipidemia, 5.3% vs 1.7%; ischemic heart disease, 1.5% vs 0.4%; obesity, 16.3% vs 7.4%) and mental health conditions (anxiety disorders, 27.9% vs 6.5%; depressive disorders, 32.1% vs 7.5%; posttraumatic stress disorder, 9.5% vs 1.2%) than people without IDD. The probability of postpartum anxiety (adjusted hazard ratio [AHR], 3.2 [95% CI, 2.9-3.4]) and postpartum depression (AHR, 2.4 [95% CI, 2.3-2.6]) was significantly higher among autistic people compared with people with ID only and people without IDD.

Conclusions and Relevance In this retrospective cohort study, people with IDD had a younger mean age at first delivery, had lower prevalence of live births, and had poor obstetric, mental health, and medical outcomes compared with people without IDD, pointing toward a need for clinician training and timely delivery of maternal health care. Results highlight needed reproductive health education, increasing clinician knowledge, and expanding Medicaid to ensure access to care for people with IDD. (Author)

Full URL: https://doi.org/10.1001/jamanetworkopen.2024.28067

2024-10307

Supporting women with learning disabilities in infant feeding decisions: UK health care professionals' experiences. Dowling S, Douglass E, Lucas G, et al (2023), Maternal & Child Nutrition vol 19, no 1, January 2023, e13424

Women with learning disabilities are less likely to breastfeed than other women. They may find it hard to understand or learn feeding techniques or know that they have infant feeding choices. This population may be supported during their pregnancies by a range of professionals with differing priorities and responsibilities towards both the mother and the baby. This puts considerable pressure on health care professionals including, but not limited to, midwives, infant feeding specialists, health visitors and learning disability nurses. Those who support women with learning disabilities through their journey into motherhood have a responsibility to ensure the women in their care have the information they need to make decisions about a range of issues, including infant feeding. In the absence of dedicated lactation consultants, this is one of many issues to be discussed within time-limited appointments. Little is known about the experience of supporting women with learning disabilities to make infant feeding decisions from the point of view of health professionals. Using a qualitative descriptive research design, we conducted online, semistructured interviews with seven UK health professionals about their experience of supporting women with learning disabilities in infant feeding. Thematic analysis identified three themes: the importance of health professionals' having unconditional, positive regard; the need for an individualised approach to supporting women to make infant-feeding decisions; and being part of the support network. This suggests that women with learning disabilities can make and put into practice infant feeding decisions if they have access to the right support at the right time. (Author)

Full URL: https://doi.org/10.1111/mcn.13424

2024-10114

Learning disability awareness training for undergraduate midwifery students: Multi-method evaluation of a co-produced and co-delivered educational intervention in England. Cox A, Tobutt D, Harris J, et al (2024), Nurse Education Today vol 140, September 2024, 106289

Background
Midwives lack the confidence and competence to identify and support people with learning disabilities, putting this population at risk of inequitable maternity care.

Objectives
To co-produce, co-deliver and evaluate maternity focused learning disability awareness training for student midwives, in collaboration with experts-by-experience (people with learning disabilities).

Design
Multi-methods study evaluating the impact and acceptability of learning disability awareness training.

Settings
University in south-east England, UK.

Participants
83 midwifery students and 7 experts-by-experience.

Methods
Midwifery students completed pre-post training surveys and a follow-up survey 3 months post training to substantiate longer-term impact. Experts-by-experience took part in qualitative interviews post training.

Results
Student-reported learning disability awareness was significantly higher across all domains post training and sustained at follow up. Students reported the most notable aspect of training was learning with and from people with learning disabilities. Three inter-related themes were constructed from interviews with experts-by-experience: reasonable adjustments to training and research processes; a positive social, emotional and learning experience; and perceptions of impact.

Conclusions
Findings from this study suggest that co-producing and co-delivering resources and education to an undergraduate midwifery workforce with people with lived experience, can have a profound impact on students and is also a positive experience for people with learning disabilities. The co-produced resources used in this training are free and accessible [
https://www.surrey.ac.uk/togetherproject
]. Further evaluation will explore acceptability and perceived impact of training and resources on other healthcare professionals working with maternity services. (Author)

Full URL: https://doi.org/10.1016/j.nedt.2024.106289

2024-09838

Supporting women with learning disabilities in infant feeding decisions: A scoping review. Johnson C, Douglass E, Lucas G, et al (2022), Maternal & Child Nutrition vol 18, no 2, April 2022, e13318

Mothers with learning disabilities face many challenges during the perinatal period including preparing for and establishing infant feeding. Evidence shows that women with learning disabilities are less likely to breastfeed than other mothers. A scoping review was undertaken using Arksey and O'Malley's methodology to understand what is known about how women with learning disabilities can be supported to make infant feeding decisions, particularly in relation to the use of appropriate and accessible images. An additional aim was to understand what further research is needed to achieve sustainable improvements to policy and practice in this area. A comprehensive search of fourteen electronic databases was undertaken to look for both published and grey literature. Initial searches, after removal of duplicates, resulted in 467 primary research articles plus 22 items of grey literature. Following a systematic process, three published papers and six items of grey literature were identified which met inclusion and exclusion criteria, five of which were resources. Little is known about the acceptability of existing resources, specifically in relation to the use of visual images. A synthesis of the grey literature and a thematic analysis of published literature was conducted and confirmed that women with learning disabilities need tailored support with infant feeding, including accessible resources and that there is a need for more in-depth research in this area. There is a high level of agreement about the importance of using easily read visual images within these resources, but little evaluation of the types of imagery used or their aesthetic histories. (Author)

Full URL: https://doi.org/10.1111/mcn.13318

2024-08452

Pregnancy Intendedness Among Racial and Ethnically Minoritized Women with Disabilities. Valentine A, Vetter M, Horner-Johnson W, et al (2024), Journal of Women's Health vol 33, no 10, October 2024, pp 1334–1343

Background: A limited number of studies have examined the prevalence of unintended pregnancy among disabled women. However, no studies to date have examined the association between pregnancy intention and disability, in combination with race and ethnicity.

Methods: We analyzed data from the National Survey of Family Growth from the period 2011–2019 to estimate the prevalence of pregnancy intendedness among women with disabilities 15–45 years of age. We compared pregnancy intendedness among respondents with and without disabilities. Modified Poisson regressions were conducted to estimate the unadjusted and adjusted prevalence ratios (with 95% confidence intervals) of unintended pregnancy across disability type and by race and ethnicity category. Non-Hispanic White women without disabilities served as the referent group.

Results: Unadjusted results found that women with disabilities in all racial or ethnic groups were significantly more likely to report unintended pregnancies compared with non-Hispanic White women with no disabilities. Non-Hispanic Black women were more than three and a half times (PR = 3.72, 95% CI: 2.91–4.75) more likely than their non-Hispanic White counterparts to report an unintended pregnancy. After adjusting for demographic characteristics, results were slightly attenuated in all categories, with the exception of nondisabled Hispanic women, indicating high prevalence of unintended pregnancies.

Conclusions: Racial and ethnic minority women with disabilities may experience heightened risk for unintended pregnancy. Targeted efforts are needed to address barriers to comprehensive sexual and reproductive health care and improve reproductive health outcomes among women who experience multiple forms of marginalization. (Author)

2024-08450

Prescription Medication Use in Pregnancy in People with Disabilities: A Population-Based Cohort Study. Camden A, Grandi SM, Lunsky Y, et al (2024), Journal of Women's Health vol 33, no 9, September 2024, pp 1224–1232

Background: Individuals with disabilities may require specific medications in pregnancy. The prevalence and patterns of medication use, overall and for medications with known teratogenic risks, are largely unknown.
Methods: This population-based cohort study in Ontario, Canada, 2004–2021, comprised all recognized pregnancies among individuals eligible for public drug plan coverage. Included were those with a physical (n = 44,136), sensory (n = 13,633), intellectual or developmental (n = 2,446) disability, or multiple disabilities (n = 5,064), compared with those without a disability (n = 299,944). Prescription medication use in pregnancy, overall and by type, was described. Modified Poisson regression generated relative risks (aRR) for the use of medications with known teratogenic risks and use of ≥2 and ≥5 medications concurrently in pregnancy, comparing those with versus without a disability, adjusting for sociodemographic and clinical factors.
Results: Medication use in pregnancy was more common in people with intellectual or developmental (82.1%), multiple (80.4%), physical (73.9%), and sensory (71.9%) disabilities, than in those with no known disability (67.4%). Compared with those without a disability (5.7%), teratogenic medication use in pregnancy was especially higher in people with multiple disabilities (14.2%; aRR 2.03, 95% confidence interval [CI]: 1.88–2.20). Furthermore, compared with people without a disability (3.2%), the use of ≥5 medications concurrently was more common in those with multiple disabilities (13.4%; aRR 2.21, 95% CI: 2.02–2.41) and an intellectual or developmental disability (9.3%; aRR 2.13, 95% CI: 1.86–2.45).
Interpretation: Among people with disabilities, medication use in pregnancy is prevalent, especially for potentially teratogenic medications and polypharmacy, highlighting the need for preconception counseling/monitoring to reduce medication-related harm in pregnancy. (Author)

2024-07694

Implementing and evaluating resources to support good maternity care for parents with learning disabilities: A qualitative feasibility study in England. Cox A, Ip A, Watkin S, et al (2024), Midwifery vol 133, June 2024, 104001

Problem

Parents with learning disabilities are often disadvantaged and their needs not well understood in maternity services.

Background

Despite a global vision to improve maternity care, current evidence confirms poor pre- and post-natal care for parents with learning disabilities and their families. Midwives have expressed a need for support in the delivery of good care to this population of parents.

Aim

To test the feasibility of implementing and evaluating two evidence-based and values-based resources – the Together Toolkit and Maternity Passport - to support good maternity care for people with learning disabilities.

Methods

A qualitative feasibility study employing semi-structured interviews with 17 midwives and 6 parents who had used the resources in practice in four NHS Trusts in the south of England.

Findings

Midwives and parents described how the resources positively impacted maternity care by enabling midwives, connecting networks and empowering parents. Factors affecting effective implementation of the resources were reported at an individual and setting level.

Discussion

Staff training to raise awareness and confidence in supporting parents with learning disabilities, and improved systems for recording parent's individual needs are required to enable the delivery of personalised care.

Conclusion

Reasonable adjustments need to be prioritised to facilitate implementation of resources to support personalised maternity care and to address inequity for parents with learning disabilities. Aspirations for equity suggested commitment from midwives to challenge and overcome barriers to implementation. Recommendations were made to improve the resources and their implementation. These resources are free and accessible for use [www.surrey.ac.uk/togetherproject]. (Author)

Full URL: https://doi.org/10.1016/j.midw.2024.104001

2024-07303

Learning disability awareness training for undergraduate midwifery students: Multi-method evaluation of a co-produced and co-delivered educational intervention in England. Cox A, Tobutt D, Harris J, et al (2024), Nurse Education Today 14 June 2024, online

Background
Midwives lack the confidence and competence to identify and support people with learning disabilities, putting this population at risk of inequitable maternity care.

Objectives
To co-produce, co-deliver and evaluate maternity focused learning disability awareness training for student midwives, in collaboration with experts-by-experience (people with learning disabilities).

Design
Multi-methods study evaluating the impact and acceptability of learning disability awareness training.

Settings
University in south-east England, UK.

Participants
83 midwifery students and 7 experts-by-experience.

Methods
Midwifery students completed pre-post training surveys and a follow-up survey 3 months post training to substantiate longer-term impact. Experts-by-experience took part in qualitative interviews post training.

Results
Student-reported learning disability awareness was significantly higher across all domains post training and sustained at follow up. Students reported the most notable aspect of training was learning with and from people with learning disabilities. Three inter-related themes were constructed from interviews with experts-by-experience: reasonable adjustments to training and research processes; a positive social, emotional and learning experience; and perceptions of impact.

Conclusions
Findings from this study suggest that co-producing and co-delivering resources and education to an undergraduate midwifery workforce with people with lived experience, can have a profound impact on students and is also a positive experience for people with learning disabilities. The co-produced resources used in this training are free and accessible [https://www.surrey.ac.uk/togetherproject. Further evaluation will explore acceptability and perceived impact of training and resources on other healthcare professionals working with maternity services. (Author)

2024-06972

The association between attention deficit hyperactivity disorder and pregnancy, delivery and neonatal outcomes—an evaluation of a population database. Amikam U, Badeghiesh A, Baghlaf H, et al (2024), BMC Pregnancy and Childbirth vol 24, no 364, May 2024

Background
Attention deficit hyperactivity disorder (ADHD) is one of the more common neuropsychiatric disorders in women of reproductive age. Our objective was to compare perinatal outcomes between women with an ADHD diagnosis and those without.

Methods
A retrospective population-based cohort study utilizing the Healthcare Cost and Utilization Project, Nationwide Inpatient Sample (HCUP-NIS) United States database. The study included all women who either delivered or experienced maternal death from 2004 to 2014. Perinatal outcomes were compared between women with an ICD-9 diagnosis of ADHD and those without.

Results
Overall, 9,096,788 women met the inclusion criteria. Amongst them, 10,031 women had a diagnosis of ADHD. Women with ADHD, compared to those without, were more likely to be younger than 25 years of age; white; to smoke tobacco during pregnancy; to use illicit drugs; and to suffer from chronic hypertension, thyroid disorders, and obesity ($p < 0.001$ for all). Women in the ADHD group, compared to those without, had a higher rate of hypertensive disorders of pregnancy (HDP) (aOR 1.36, 95% CI 1.28–1.45, $p < 0.001$), cesarean delivery (aOR 1.19, 95% CI 1.13–1.25, $p < 0.001$), chorioamnionitis (aOR 1.34, 95% CI 1.17–1.52, $p < 0.001$), and maternal infection (aOR 1.33, 95% CI 1.19–1.5, $p < 0.001$). Regarding neonatal outcomes, patients with ADHD, compared to those without, had a higher rate of small-for-gestational-age neonate (SGA) (aOR 1.3, 95% CI 1.17–1.43, $p < 0.001$), and congenital anomalies (aOR 2.77, 95% CI 2.36–3.26, $p < 0.001$).

Conclusion
Women with a diagnosis of ADHD had a higher incidence of a myriad of maternal and neonatal complications, including cesarean delivery, HDP, and SGA neonates. (Author)

Full URL: https://doi.org/10.1186/s12884-024-06561-5

2024-05278

Vitamin D levels of pregnant immigrant women and developmental disorders of language, learning and coordination in offspring. Arrhenius B, Surcel HM, Hinkka Yli-Salomäki S, et al (2024), PLoS ONE vol 19, no 2, February 2024, e0299808

Background: Prenatal vitamin D deficiency is a common health concern among immigrants. No previous studies have examined the associations between prenatal vitamin D levels and developmental disorders of language, scholastic skills, and coordination in an immigrant sample.

Methods: The sample included 542 immigrant mothers of cases with language, scholastic, coordination or mixed developmental disorders, 443 immigrant mothers of controls without these disorders and 542 Finnish mothers of controls. Maternal vitamin D was measured in serum samples collected during early pregnancy and stored in a national biobank.

Results: The mean vitamin D levels during pregnancy were 25.0 (SD 14.4) nmol/L for immigrant mothers of cases, 25.4 (SD 15.5) for immigrant mothers of controls and 42.3 (SD 19.1) for Finnish mothers of controls. Low maternal vitamin D levels during pregnancy were not associated with the selected developmental disorders in offspring when immigrant mothers of cases were compared to immigrant mothers of controls (adjusted OR for continuous log-transformed vitamin D: 1.01, 95% CI 0.75-1.36, p = 0.96). When immigrant mothers of cases were compared to Finnish mothers of controls, the adjusted OR for continuous vitamin D was 18.94 (95% CI 11.47-31.25), p <0.001). The results were similar when vitamin D was examined as a categorical variable or divided into quintiles.

Conclusions: Prenatal vitamin D levels were low, and similar, among immigrant mothers of cases with selected developmental disorders and unaffected controls. This indicates that vitamin D unlikely mediates previously observed associations between maternal immigrant status and the selected developmental disorders in offspring. The proportion of immigrant mothers with severe vitamin D deficiency was very high, which underlines the importance of prenatal counselling and overall public health efforts to improve immigrant health.

Full URL: https://doi.org/10.1371/journal.pone.0299808

2024-04297

A Capture of Midwifery Care in Women with Disabilities in Southeast Asia. Ambarwati K, Wijayanti FA (2024), International Confederation of Midwives (ICM), The Hague, 1 April 2024

Discusses the midwifery care of women with disabilities in Indonesia and Nepal, advocating for inclusive practices to ensure the rights and well-being of all women. (MB)

Full URL: https://internationalmidwives.org/a-capture-of-midwifery-care-in-women-with-disabilities-in-southeast-asia/

2024-04280

Autistic women's experiences of the antenatal, intrapartum and early postnatal periods. Stuart V, Kitson-Reynolds E (2024), British Journal of Midwifery vol 32, no 4, April 2024, pp 180–188

Background/Aims

Autism is a neurodevelopmental disability affecting interpersonal communication and interaction, and has a prevalence of more than 1% of the population. This review aimed to identify what midwives in England can learn from studies exploring the experiences of autistic women in the antenatal, intrapartum and early postnatal periods.

Methods

A systematic literature search was conducted using seven electronic databases. Thematic analysis was performed, based on Braun and Clarke.

Results

Three themes were found: autism diagnosis and disclosure, communication and interaction with healthcare professionals, babies and groups, and sensory difficulties.

Conclusions

Autistic women experience many challenges during the antenatal, intrapartum and early postnatal periods, and it is clear that midwives in England should treat all women as an individual, asking about their specific needs and any adjustments that can be made to provide inclusive care. (Author)

2024-00736

Identifying women with a disability in Australian maternity services: Time for a change. Benzie CA, Newton MS, McLachlan HL, et al (2024), Australian and New Zealand Journal of Obstetrics and Gynaecology (ANZJOG) vol 64, no 3, June 2024, pp 293-296

It is estimated that over 1 billion people worldwide have a disability. In Australia, 9% of women of childbearing age have a disability, but data on disability status for women accessing maternity services are not routinely collected and data collection processes are inconsistent. Maternal disability may affect perinatal outcomes, but to understand what factors might be amenable to interventions to improve outcomes, accurate data collection on disability status is essential. This opinion piece reflects on disability identification within maternity services in Australia, identifying areas for policy and practice change. (Author)

2024-00388

Maternal disability and initiation and duration of breastfeeding: analysis of a Canadian cross-sectional survey. Brown HK, Pablo L, Scime NV, et al (2023), International Breastfeeding Journal vol 18, no 70, December 2023

Background
The World Health Organization recommends breastfeeding as the best method for infant feeding. Known risk factors for breastfeeding non-initiation and early cessation of breastfeeding are diverse and include low breastfeeding self-efficacy, poverty, smoking, obesity, and chronic illness. Although women with disabilities experience elevated rates of these risk factors, few studies have examined their breastfeeding outcomes. Our objective was to examine breastfeeding non-initiation and early cessation of breastfeeding in women with and without disabilities.

Methods
We used data from the 2017–2018 Canadian Community Health Survey. Included were n = 4,817 women aged 15–55 years who had a birth in the last five years, of whom 26.6% had a disability, ascertained using the Washington Group Short Set on Functioning. Prevalence ratios (aPR) of breastfeeding non-initiation, and of early cessation of any and exclusive breastfeeding before 6 months, were calculated for women with versus without disabilities. We also examined disability by severity (moderate/severe and mild, separately) and number of action domains impacted (≥ 2 and 1, separately). The main multivariable models were adjusted for maternal age, marital status, level of education, annual household income level, and immigrant status.

Results
There were no differences between women with and without disabilities in breastfeeding non-initiation (9.6% vs. 8.9%; aPR 0.88, 95% CI 0.63, 1.23). Women with disabilities were more likely to have early cessation of any (44.4% vs. 35.7%) and exclusive breastfeeding before 6 months (66.9% vs. 61.3%), with some attenuation in risk after adjustment for sociodemographic factors (aRR 1.15, 95% CI 0.99, 1.33 and aRR 1.07, 95% 0.98, 1.16, respectively). Disparities were larger for women with moderate/severe disabilities and disabilities in ≥ 2 domains, with differences attenuated by adjustment for socio-demographics.

Conclusions
Women with disabilities, and particularly those with moderate/severe and multiple disabilities, could benefit from tailored, accessible breastfeeding supports that attend to the social determinants of health. (Author)

Full URL: https://doi.org/10.1186/s13006-023-00608-7

2023-13388

“Work with us… to make it more accessible”. What women with intellectual disabilities want from infant-feeding health resources: an exploratory study. Douglass E, Johnson C, Lucas G, et al (2023), International Breastfeeding Journal vol 18, no 67, December 2023

Background
More women with intellectual disabilities are becoming mothers but fewer are known to breastfeed compared with other women. Women with intellectual disabilities are entitled to accessible antenatal and infant feeding information, yet are rarely asked for their views on available resources. This article reports on the final stage of a UK project exploring how women with intellectual disabilities are supported to make infant feeding decisions. The wider project includes a scoping review and interviews with healthcare professionals, here we focus on the voices of the women themselves.

Methods
Four women with an intellectual disability participated in a focus group where they were asked to give their views on the accessibility of currently available infant feeding resources and on alternative representations of infant feeding. All were interested in women’s health issues, including infant feeding. Photo-elicitation was used to gather views on videos, bespoke ‘Easy Read’ material and several alternative representations of infant feeding. A transcription of the discussion was thematically analysed whilst a critical visual analysis was undertaken of the women’s preferred images/resources. The study took place in Bristol, UK, during 2022.

Results
Two themes were identified from the group discussion: ‘The desire for choice’ and ‘How easy is ‘Easy Read’?’ The desire for choice was expressed in terms through agreements and disagreements about preferred imagery, differing tastes, and reasons for these preferences. We identified a challenge to ‘Easy Read’ as a default standard and concerns that some forms of ‘Easy Read’ can confuse rather than inform. Critical visual analysis identified the importance of the story and social setting of the preferred infant feeding image.

Conclusions
Findings suggest a need for a suite of resources, avoiding the one-size-fits-all approach, including people with an intellectual disability at every stage of the design and production process. Resources should recognise and embrace differences in terms of understanding, visual literacy and cultural taste, as well as being freely available to support women with intellectual disabilities to make informed infant feeding decisions. An accessible film was co-produced, to disseminate the findings from all three stages of the completed project. (Author)

Full URL: https://doi.org/10.1186/s13006-023-00606-9

2023-11646

A Socio-Ecological Approach to Understanding the Perinatal Care Experiences of People with Intellectual and/or Developmental Disabilities in Ontario, Canada. Khan M, Brown HK, Lunsky Y, et al (2021), Women's Health Issues vol 31, no 6, November 2021, pp 550-559

Background: Accessible and quality care during the perinatal period is critical for optimal maternal and neonatal health. Using the socio-ecological model, the purpose of this study was to explore barriers and facilitators that shape the perinatal care experiences of people with intellectual and/or developmental disabilities (IDD).

Methods: Semi-structured interviews were conducted with 10 individuals with IDD in Ontario, Canada, who had given birth within the past 5 years. Interviews focused on care experiences before, during, and after pregnancy. Data were analyzed using a directed content analysis approach, and the socio-ecological model guided analysis.

Results: Barriers at the societal (e.g., cultural norms of motherhood), policy/institutional (e.g., child protection policies and practices), interpersonal (e.g., inadequate formal and informal support), and intrapersonal levels (e.g., internalized stigma) contributed to participants having negative perinatal care experiences. Conversely, we identified facilitators on the interpersonal level (e.g., positive interactions with perinatal care providers and familial and social service supports) as positively shaping participants' perinatal care experiences.

Conclusions: Findings reveal that the perinatal care experiences of people with IDD are shaped by several interrelated factors that largely stem from societal-level barriers, such as dominant (stigmatizing) discourses of disability. To improve the perinatal care experiences of people with IDD, there is a need for interventions at multiple levels. These include the development of policies to support perinatal care for diverse populations and training care providers to enact policies at the institutional and interpersonal levels.

2023-11448

Experiences of Breastfeeding among Disabled Women. Andrews EE, Powell RM, Ayers KB, et al (2021), Women's Health Issues vol 31, no 1, January-February 2021, pp 82-89

Background

Although breastfeeding has been extensively studied, there remains a paucity of data about the breastfeeding experiences of disabled women. Despite indications of similar pregnancy rates, disabled women seem to breastfeed at lower rates. Emerging research on the intersection of breastfeeding and disability has begun to shed light on how aspects of disability may impact breastfeeding.

Methods

This digital and participatory action research study used semistructured video or telephone interviews to evaluate the experiences of breastfeeding among 24 disabled women through descriptive content analysis. The cross-disability sample was composed of women with self-identified intellectual, developmental, physical, sensory, and psychiatric disabilities. Some women had multiple disabilities.

Results

Qualitative analysis revealed four themes relating to breastfeeding among disabled women: 1) communication difficulties with lactation consultants, 2) milk supply and latch problems, 3) intense pressure to breastfeed, and 4) positive interactions with health care providers.

Conclusions

This study provides new information about the breastfeeding experiences of women with disabilities. Our findings suggest that disabled women should be better supported in their breastfeeding decisions and require greater access to disability-affirmative and informative clinical resources and accessible communication. (Author)

2023-10211

Pregnancy Outcomes in Canadian Women With Disabilities: Results From Linked Survey and Health Administrative Data. Brown HK, Forbes SM, Evans M, et al (2023), JOGC [Journal of Obstetrics and Gynaecology Canada] vol 45, no 10, October 2023, 102179

We compared maternal, labour/delivery, and birth outcomes in women with versus without disabilities using a linkage of 2003–2014 Canadian Community Health Survey (CCHS) and 2003–2017 Discharge Abstract Database data. Modified Poisson regression was used to compare 15–49-year-old women with (n = 2430) and without (n = 10 375) disabilities with a singleton birth ≤5 years after their CCHS interview. Women with disabilities were at elevated risk of prenatal hospitalization (10.3% vs. 6.6%; adjusted prevalence ratio 1.33, 95% CI 1.03–1.72). They were also at elevated risk of preterm birth (8.7% vs. 6.2%), but this was attenuated after adjustment. Women with disabilities could benefit from tailored prenatal care. (Author)

2023-09069

Comparison of Emergency Department Use Between Pregnant People With and Without Disabilities in Ontario, Canada. Brown HK, Varner C, Ray JG, et al (2023), JAMA Network Open vol 6, no 8, August 2023, e2327185

Importance Emergency department (ED) use in pregnancy is common and occurs for a variety of reasons, including obstetrical complications, exacerbated underlying conditions, and inadequate outpatient health care access. People with disabilities have elevated rates of certain medical, psychiatric, and obstetrical conditions as well as inadequate access to prenatal care; their risk of ED use in pregnancy is not known, however.

Objective To compare the risk of ED use in pregnancy among people with physical, sensory, and intellectual or developmental disabilities with those without disabilities.

Design, Setting, and Participants Population-based cohort study leveraging linked administrative health data sets in Ontario, Canada, April 2003 to March 2019. Analysis included all recognized pregnancies to people with a preexisting physical, sensory, intellectual or developmental, or 2 or more (multiple) disabilities, and those without a disability. Data were analyzed from May 2022 to January 2023.

Exposure Disability was ascertained using algorithms applied to 2 or more outpatient physician visits or 1 or more ED visits or hospitalizations before conception.

Main outcomes and measures Modified Poisson regression–generated adjusted relative risks (aRR) and 95% CIs for any ED visit in pregnancy, from the estimated conception date up to the end of the pregnancy, adjusted for age, parity, income quintile, rurality, immigrant status, and preexisting chronic conditions, mental illness, and substance use disorders.

Results The cohort included 2 659 895 pregnant people with physical (221 739 participants; mean [SD] age, 29.8 [6.1] years), sensory (71 891 participants; mean [SD] age, 29.1 [6.4] years), intellectual or developmental (3877 participants; mean [SD] age, 26.1 [6.7] years), and multiple disabilities (14 359 participants; mean [SD] age, 29.5 [6.5] years), and pregnant people without a disability (2 348 023 participants; mean [SD] age, 29.4 [5.9] years). The rate of ED visits in pregnancy was 25.4% in people without a disability (596 771 visits). Relative to these individuals, the aRR for ED use was elevated in people with physical (aRR, 1.26; 95% CI, 1.25-1.27), sensory (aRR, 1.15; 95% CI, 1.14-1.17), intellectual or developmental (aRR, 1.33; 95% CI, 1.28-1.38), and multiple disabilities (aRR, 1.43; 95% CI, 1.40-1.46).

Conclusions and Relevance In this population-based study, people with disabilities were at elevated risk of ED use in pregnancy. This finding underscores the need for research on the benefits of proactive strategies to manage preexisting conditions in these individuals, improve their access to outpatient obstetrical and medical care, and prepare them for when ED visits occur. (Author)

Full URL: https://doi.org/10.1001/jamanetworkopen.2023.27185

2023-04329

Prenatal Care Experiences of Childbearing People With Disabilities in Ontario, Canada. Tarasoff LA, Saeed G, Lunsky Y, et al (2023), JOGNN: Journal of Obstetric, Gynecologic and Neonatal Nursing vol 52, no 3, May 2023, pp 235-247

Objective

To explore the care experiences of childbearing people with physical, sensory, and/or intellectual/developmental disabilities during pregnancy.

Design

Descriptive qualitative.

Setting

Ontario, Canada, where physician and midwifery care during pregnancy are provided at no direct cost to residents.

Participants

Thirty-one people with physical, sensory, and/or intellectual/developmental disabilities (who self-identified as cisgender women [n = 29] and trans or nonbinary persons [n = 2]) who gave birth in the last 5 years.

Methods

We recruited childbearing people with disabilities through disability and parenting organizations, social media, and our team's networks. Using a semistructured guide, we conducted in-person and virtual (e.g., telephone or Zoom) interviews with childbearing people with disabilities in 2019 to 2020. We asked participants about the services they accessed during pregnancy and if services met their needs. We used a reflexive thematic analysis approach to analyze interview data.

Results

Across disability groups, we identified four common themes: Unmet Accommodation Needs, Lack of Coordinated Care, Ableism, and Advocacy as a Critical Resource. We found that these experiences manifested in unique ways based on disability type.

Conclusion

Our findings suggest the need for accessible, coordinated, and respectful prenatal care for people with disabilities, with the requirements of such care depending on the needs of the individual person with a disability. Nurses can play a key role in identifying the needs and supporting people with disabilities during pregnancy. Education and training for nurses, midwives, obstetricians, and other prenatal care providers should focus on disability-related knowledge and respectful prenatal care. (Author)

2023-02350

Effective communication: Core to promoting respectful maternity care for disabled women. Collins B, Hall J, Hundley V, et al (2023), Midwifery vol 116, January 2023, 103525

Objective

Previous research highlights that disabled women have less choice, control and respect of their dignity during pregnancy, childbirth and parenting. The experience of dignity and respect during pregnancy and childbirth for those with physical and sensory disability in the UK and Ireland is explored.

Design, setting and participants

Narrative, semi-structured telephone and Skype interviews were conducted with ten disabled women in the UK and Ireland. Interviews were audio-recorded and transcribed verbatim. Intra- and inter-thematic analysis was undertaken, beginning with a process of open coding. As themes developed, a process of constant comparison was used.

Findings

The key finding is that effective communication with women was perceived to best respect the women's dignity in childbirth. This meant enabling women to feel heard, enabling women to make informed decisions about their care and providing individualized care. The single most important factor that enabled this communication was continuity of carer.

Key Conclusions

The factor that most promoted maternity care that was perceived to be respectful was effective communication. This is not so different in other parts of the world, or for non-disabled women, however care providers should be particularly careful to enable good communication with disabled women. (Author)

Full URL: https://doi.org/10.1016/j.midw.2022.103525

2022-11129

Pregnancy: discrimination [written answer]. Scottish Parliament (2022), Official Report Written question S6W-12779, 1 December 2022

Maree Todd responds to a written question from Monica Lennon to the Scottish Government, in light of the Public Health Scotland report, Births in Scotland, whether it will review any discrimination against people with mental health issues and learning disabilities during pregnancy, which was last reviewed in 2013. (MB)

Full URL: https://archive2021.parliament.scot/parliamentarybusiness/28877.aspx?SearchType=Advance&ReferenceNumbers=S6W-12779

2022-10625

Human Rights in Childbearing 3. Providing Sensitive Antenatal Care for Autistic Women and Birthing People. Rayner S, Porter N, Edwards E (2022), The Practising Midwife vol 25, no 10, November 2022, pp 14-17

Autistic people face significant disparities in their experiences of healthcare services compared to non-autistic people, with autistic adults reporting lower satisfaction with staff communication, and higher odds of unmet healthcare needs relating to their physical health, mental health, and prescription medications.1 These difficulties are also apparent when accessing perinatal care services. It is essential that we address this ensuring the protected characteristic of disability under the Equality Act 2010 is honoured. In this article, Sophie Rayner, Nicolette Porter and Emilie Edwards discuss how midwives can provide sensitive antenatal care for autistic women and birthing people. (Author)

2022-09146

Maternity Services: Deaf and Disabled Women (Northern Ireland) [written answer]. Northern Ireland Assembly (2022), Hansard Written question AQW 3244/22-27, 20 September 2022

The Minister of Health responds to a written question from Ms Emma Sherrin to the Northern Ireland Assembly, regarding what measures are in place to ensure that maternity services are accessible for deaf and disabled women. (JSM)

Full URL: http://aims.niassembly.gov.uk/questions/printquestionsummary.aspx?docid=380851

2022-06841

Obstetric violence and disability overlaps: obstetric violence during child birth among womens with disabilities: a qualitative study. Wudneh A, Cherinet A, Abebe M, et al (2022), BMC Women's Health vol 22, no 299, 18 July 2022

Introduction

Obstetric violence is an invisible wound which is being distorting the quality of obstetric care. Obstetric Violence, which is an issue spoken and amplified currently as a type of sexual violence and is of alarming seriousness and is an evolving field of inquiry despite women's experience of institutional childbirth, has garnered unprecedented global attention in recent years. Losing on both counts: obstetric violence is a double burden among disabled women.

Aim

To explore the experience of disabled women towards obstetric violence during child birth in Gedio zone, South Ethiopia.

Methods

Twenty-two (22) women with disabilities were interviewed. They were recruited through a nonprobability snowball sampling method. The interviews were conducted using a structured questionnaire in the Gedio zone, south Ethiopia. For coding purposes, NVivo (version 11) software was employed. Using a method known as continuous comparison, we classified the extracted codes based on their similarities and differences. The classes were then arranged in such a way that there was the greatest internal uniformity and the least external mismatch.

Results

The profile of the study group is predominantly of women between the ages of 21 and 30. Physical abuse, verbal abuse, stigma and discrimination, neglect and abandonment, and violations of privacy were the five major categories emerged during the thematic analysis describing the experience of obstetric violence. Women also observed these forms of obstetric violence among other disabled women during child birth. In addition to the violations of care, some of the participants described positive aspects of their childbirth experiences in one or more obstetric care settings.

Conclusion

This study concluded that the quality of service was deplorable, with reports of obstetric violence among this vulnerable group of women imposing a double burden on them. The findings suggest that there is a need to improve maternity care for disabled women by implementing comprehensive, culturally sensitive, client-sensitive special services and providing sensitivity training to healthcare providers, ensuring satisfied, equitable, and quality obstetric care. (Author)

Full URL: https://doi.org/10.1186/s12905-022-01883-y

2022-06670

Intimate partner violence during the perinatal period by disability status: Findings from a United States population-based analysis. Alhusen JL, Lyons G, Laughon K, et al (2023), Journal of Advanced Nursing vol 79, no 4, April 2023, pp 1493-1502

Aims
The aim of the current study was to compare the prevalence of intimate partner violence (IPV) during the perinatal period among respondents with self-reported disability compared with those without a disability.

Design
We conducted a secondary analysis of nationally representative data from the Pregnancy Risk Assessment Monitoring System data from 24 participating United States between 2018 and 2020.

Methods
A cross-sectional sample of 43,837 respondents provided data on disability, including difficulty in vision, hearing, ambulation, cognition, communication and self-care. The exposure was perinatal IPV, defined as experiencing abuse by a current or ex-partner in the year before or during pregnancy. Regression models were used to calculated odds of IPV by disability status while accounting for relevant sociodemographic characteristics.

Results
Respondents who self-reported disabilities experienced IPV at a higher rate than those without disabilities, both before and during pregnancy. In fully adjusted models, respondents with disabilities had about 2.6 times the odds of experiencing IPV before pregnancy, and about 2.5 times the odds of experiencing IPV during pregnancy, compared with those without disabilities.

Conclusion
Respondents with disabilities experienced IPV at higher rates than the general population, and thus are at increased risk for adverse maternal, neonatal and infant health outcomes.

Impact
Perinatal IPV is a significant issue globally, and our findings suggest perinatal IPV is particularly salient for persons with disability. Findings highlight the need to screen women with disabilities for IPV during the perinatal period as well as the importance of providing them appropriate, accessible information, resources and referrals. (Author)

Full URL: https://doi.org/10.1111/jan.15340

2022-06070

How are women with a disability identified in maternity services in Australia? A cross-sectional survey of maternity managers.

Benzie C, Newton M, Forster D, et al (2023), Women and Birth: Journal of the Australian College of Midwives vol 36, no 1, February 2023, pp e161-e168

Background

Women with a disability have poorer perinatal outcomes, but little is known about the prevalence of women with a disability accessing maternity services, how they are identified and what care and services are available. Estimates suggest that nine percent of women of childbearing age have a disability.

Aim

To explore how public maternity services in Australia identify pregnant women with a disability, what (if any) routine disability identification questions are used, and to examine availability and adequacy of services for women.

Methods

Cross-sectional online survey of maternity managers in Australian public hospitals.

Findings

Thirty-six percent (70/193) of eligible hospitals responded including all states and territories. Overall, 71 % routinely asked women about disability status (usually as part of routine history taking), however there was wide variation in how this was asked. Most (63 %) did not have standardised documentation processes and two thirds (65 %) were unable to estimate the number of women with a disability seen at their hospital. Most (68 %) did not offer specialised services, with only 13 % having specialised training for staff in disability identification, documentation and referral pathways. Only a quarter of respondents felt that there were adequate services for women with a disability related to maternity care.

Conclusion

This is the first study to explore disability identification in maternity services in Australia. How women were asked was highly varied and documentation not standardised. National guidelines on disability identification for women accessing maternity services should be developed and collection of disability identification data should be routine. (Author)

2022-04170

Barriers to and facilitators of effective communication in perinatal care: a qualitative study of the experiences of birthing people with sensory, intellectual, and/or developmental disabilities. Saeed G, Brown HK, Lunsky Y, et al (2022), BMC Pregnancy and Childbirth vol 22, no 364, 26 April 2022

Background
Effective provider-patient communication is a key element of quality health care, including perinatal care. What constitutes "effective communication" in perinatal care may vary according to the population seeking care, such as women with intellectual and developmental disabilities (IDD) and sensory disabilities. Research broadly indicates that communication issues are among the barriers to perinatal care experienced by women with disabilities. However, few studies have explicitly explored their communication experiences in this context. The purpose of this study was to understand the communication experiences of birthing people with IDD and/or sensory disabilities in perinatal care.

Methods
We conducted semi-structured interviews with 17 people with IDD (e.g., autism, cognitive delay) and/or sensory disabilities (e.g., d/Deaf, blind) in Ontario, Canada, who had recently given birth, to explore barriers to and facilitators of effective communication in perinatal care. A combination of deductive and inductive thematic analysis guided data analysis.

Results
We found that birthing people with IDD and/or sensory disabilities encountered multiple barriers to effective communication in perinatal care, namely, lack of policies and guidelines, lack of provider experience, lack of provider effort, as well as ableism and provider assumptions. Facilitators included knowledgeable, aware, and supportive providers; access to communication aids and services; tailoring information to patients' disability-related communication needs; empathic communication; and, communication among providers.

Conclusion
Unmet communication needs may contribute to negative health and social outcomes for birthing people with disabilities and their newborns. Accessibility policy implementation and practice change are needed to meet the communication needs of people with IDD and/or sensory disabilities in perinatal care to ensure positive experiences and outcomes. (Author)

Full URL: https://doi.org/10.1186/s12884-022-04691-2

2022-03378

Severe maternal morbidity and other perinatal complications among women with physical, sensory, or intellectual and developmental disabilities. Homer-Johnson W, Garg B, Darney BG, et al (2022), Paediatric and Perinatal Epidemiology vol 36, no 5, September 2022, pp 759-768

Background
Little is known about severe maternal morbidity (SMM) among women with disabilities.

Objective
We assessed differences in SMM and other perinatal complications by presence and type of disability. We hypothesised that SMM and other complications would be more common in births to women with disabilities than to women without disabilities.

Methods
We conducted a retrospective cohort study of California births from 2000 to 2012, using birth and death certificate data linked with hospital discharge data. We included singleton deliveries with gestational age of 23–42 weeks. We classified women as having any disability or not and identified disability type (physical, hearing, vision, intellectual/developmental disabilities [IDD]). Our primary outcome was a composite indicator of SMM. Secondary outcomes included additional perinatal complications: gestational hypertension, preeclampsia, gestational diabetes, venous thromboembolism, chorioamnionitis, puerperal endometritis and mental health disorders complicating pregnancy, childbirth or the puerperium. We used modified Poisson regression to obtain covariate-adjusted relative risks (RR) and 95% confidence intervals (CI) for the association of disability status and type with SMM and secondary outcomes.

Results
Of 5,787,090 deliveries, 33,044 (0.6%) were to women with disabilities. Of these, 311 per 10,000 were complicated by SMM, compared with 84 per 10,000 deliveries to women without disabilities. In multivariable analyses, risk of SMM for births to women with disabilities was nearly three times that for women without disabilities (RR 2.84, 95% CI 2.67, 3.02). Proportion and risk of SMM were greatest for vision disability (793 per 10,000; RR 4.04, 95% CI 3.41, 4.78). Secondary outcomes were also more common among women with disabilities. In particular, more than a third of births to women with IDD (37.4%) were complicated by mental health disorders (versus 2.2% for women without disabilities).

Conclusion
As hypothesised, SMM and other perinatal complications were more common among women with disabilities than among women without disabilities. (Author)

Full URL: https://doi.org/10.1111/ppe.12873

2022-02053

Mellow Futures – An adapted parenting programme for mothers with learning difficulties in England and Scotland. Professionals' views on the outcomes. Tarleton B, Heslop P, et al (2021), Health and Social Care in the Community vol 29, no 5, September 2021, pp 1275-1284

The Mellow Futures programme is a specially adapted parenting programme for mothers with learning difficulties that combines group work with home-based support. This paper reports on the findings of prospective and retrospective interviews with professionals who had referred mothers to the programme in England or Scotland between 2013 and 2015. The aim was to explore their perceptions of the programme as a whole, and its impact on the mothers they had referred to it. Mothers attending the Mellow Futures programme were invited to consent for a key professional to be contacted as part of the evaluation, generally those social workers who had referred the mothers to the programme. The ‘referrers’ were interviewed at the start and end of the programme. Thirty referrers contributed their views on the impact of the programme. Twenty-six were very positive about the impact of the Mellow Futures programme on the mothers: the programme was thought to have increased the mothers' confidence and self-esteem; supported them to work through issues; and helped them strengthen their relationship-building skills. Four referrers felt that the programme had not had any impact on the mothers they were supporting. The Mellow Futures programme focused on relationships, rather than parenting techniques, and three fundamentally important relationships in the mothers and babies' lives were targeted: the relationship/attachment between mother and baby; the supportive, ongoing relationships between the mothers in the group; and the mothers' more positive engagement with the professionals concerned with the welfare of their baby. The research confirms that, from the perspectives of referrers, linking group and home-based support can successfully help mothers with learning difficulties to care for their children. (Author)

2022-01943

A population-based analysis of postpartum acute care use among women with disabilities. Brown HK, Chen S, Vigod SN, et al (2022), American Journal of Obstetrics & Gynecology MFM vol 4, no 3, May 2022, 100607

BACKGROUND

Disability is common in reproductive-aged women, and as many as 1 in 8 pregnancies occur in women with a disability. Women with disabilities experience significant social and health disparities, and are at greater risk than their nondisabled counterparts for perinatal complications. Yet, few studies have examined their postpartum acute care use.

OBJECTIVE

To examine risks of postpartum emergency department visits and hospital admissions among women with and without physical, sensory, and intellectual/developmental disabilities.

STUDY DESIGN

In this population-based study in Ontario, Canada, women with a singleton obstetrical delivery from 2003 to 2019 were classified into those with physical (n=155,500), sensory (n=49,338), intellectual/developmental (n=2650), and multiple disabilities (≥2 disabilities; n=9904), and women without disabilities (n=1,701,574). Primary outcomes were emergency department visits and hospital admissions 0 to 365 days after index delivery hospital discharge. Secondary outcomes were emergency department visits and hospital admissions by primary diagnosis (medical, psychiatric) and by timing (0–7, 8–42, 43–365 days postpartum). Adjusted relative risks comparing each disability group to those without disabilities were adjusted for age; parity; income quintile; rurality; immigrant/refugee status; prepregnancy chronic medical conditions, mental illness, and substance use disorders; and prenatal care provider type.

RESULTS

Any postpartum emergency department visit occurred in 23.5% of women without a disability, with risks elevated in women with physical (32.9%; adjusted relative risk, 1.27; 95% confidence interval, 1.26–1.28), sensory (30.0%; adjusted relative risk, 1.16; 95% confidence interval, 1.15–1.18), intellectual/developmental (48.8%; adjusted relative risk, 1.38; 95% confidence interval, 1.33–1.44), and multiple disabilities (42.0%; adjusted relative risk, 1.44; 95% confidence interval, 1.41–1.48) compared with women without disabilities. Similarly, any postpartum hospital admission occurred in 3.0% of women without a disability, with elevated risks in women with physical (4.8%; adjusted relative risk, 1.37; 95% confidence interval, 1.34–1.40), sensory (4.0%; adjusted relative risk, 1.19; 95% confidence interval, 1.14–1.24), intellectual/developmental (9.6%; adjusted relative risk, 1.96; 95% confidence interval, 1.73–2.21), and multiple disabilities (7.3%; adjusted relative risk, 1.77; 95% confidence interval, 1.64–1.90). Results were consistent by primary diagnosis and timing in the postpartum period.

CONCLUSION

Women with disabilities have elevated risk of emergency department visits and hospital admissions in the postpartum period, indicating greater postpartum morbidity, which requires attention through enhanced and extended follow-up across the postpartum period. (Author)

2022-01702

Prenatal Care Adequacy Among Women With Disabilities: A Population-Based Study. Nishat F, Lunsky Y, Tarasoff LA, et al (2022), American Journal of Preventive Medicine vol 62, no 1, January 2022, pp 39-49

Introduction

This study examines prenatal care adequacy among women with physical, sensory, and intellectual/developmental disabilities, compared with that among women without disabilities.

Methods

A population-based cohort study using linked health administrative data in Ontario, Canada was completed. The study population comprised women with physical (n=83,752), sensory (n=25,685), intellectual/developmental (n=1,219), and multiple (n=4,966) disabilities and women without disabilities (n=953,766), with a birth in 2003–2017. Analyses were conducted in 2020. Women with disabilities were identified using algorithms applied to healthcare encounters before conception. The main outcome was prenatal care adequacy, measured using the Revised Graduated Prenatal Care Utilization Index. Multivariable nominal logistic regression was used to compute the AORs and 95% CIs for no, inadequate, and intensive (versus adequate) care comparing each disability group with women without disabilities, adjusting for sociodemographic and health characteristics.

Results

Women with physical disabilities, compared with those without disabilities, had increased odds of intensive prenatal care (AOR=1.22, 95% CI=1.19, 1.24) and decreased odds of no prenatal care (AOR=0.94, 95% CI=0.89, 0.99) versus adequate care. Women with sensory disabilities had increased odds of intensive (AOR=1.11, 95% CI=1.08, 1.14), inadequate (AOR=1.06, 95% CI=1.02, 1.09), and no (AOR=1.24, 95% CI=1.14, 1.35) prenatal care. Women with intellectual/developmental disabilities had increased odds of inadequate (AOR=1.25, 95% CI=1.08, 1.44) and no (AOR=1.64, 95% CI=1.16, 2.34) prenatal care. Women with multiple disabilities had increased odds of intensive (AOR=1.41, 95% CI=1.32, 1.51) and inadequate (AOR=1.14, 95% CI=1.05, 1.22) prenatal care.

Conclusions

There are variations in prenatal care adequacy by maternal disability status. Disparities in prenatal care access for women with disabilities, particularly those with intellectual/developmental disabilities, need to be addressed. (Author)

2022-01701

Severe Maternal Morbidity and Maternal Mortality in Women With Intellectual and Developmental Disabilities. Mitra M, Akobirshoev I, Valentine A, et al (2021), American Journal of Preventive Medicine vol 61, no 6, December 2021, pp 872-881

Introduction

Despite increased attention on severe maternal morbidity and maternal mortality, scant research exists on adverse maternal outcomes in women with disabilities. This study compares the rates of severe maternal morbidity and maternal mortality in women with and without intellectual and developmental disabilities.

Methods

This study used 2004–2017 Healthcare Cost and Utilization Project Nationwide Inpatient Sample data. Analyses were conducted in 2019–2020. The risk of severe maternal morbidity with and without blood transfusion and maternal mortality during delivery among women with and without intellectual and developmental disabilities were compared using modified Poisson regression analysis.

Results

This study identified 32,324 deliveries to women with intellectual and developmental disabilities. Per 10,000 deliveries, 566 deliveries with severe maternal morbidity occurred in women with intellectual and developmental disabilities compared with 239 in women without intellectual and developmental disabilities. Women with intellectual and developmental disabilities had greater risk of both severe maternal morbidity (risk ratio=2.36, 95% CI=2.06, 2.69) and nontransfusion severe maternal morbidity (risk ratio=2.95, 95% CI=2.42, 3.61) in unadjusted analyses, which was mitigated in adjusted analyses for sociodemographic characteristics (risk ratio=1.74, 95% CI=1.47, 2.06; risk ratio=1.85, 95% CI=1.42, 2.41) and the expanded obstetric comorbidity index (risk ratio=1.23, 95% CI=1.04, 1.44; risk ratio=1.31, 95% CI=1.02, 1.68). The unadjusted incidence of maternal mortality in women with intellectual and developmental disabilities was 284 per 100,000 deliveries, nearly 4-fold higher than in women without intellectual and developmental disabilities (69 per 100,000 deliveries; risk ratio=4.07, 95% CI=2.04, 8.12), and the risk remained almost 3-fold higher after adjustment for sociodemographic characteristics (risk ratio=2.86, 95% CI=1.30, 6.29) and the expanded obstetric comorbidity index (risk ratio=2.30, 95% CI=1.05, 5.29).

Conclusions

Women with intellectual and developmental disabilities are at increased risk of severe maternal morbidity and maternal mortality. These findings underscore the need for enhanced monitoring of the needs and maternal outcomes of women with intellectual and developmental disabilities in efforts to improve maternal health. (Author)

2021-13492

Risk of Adverse Maternal Outcomes in Pregnant Women With Disabilities. Gleason JL, Grewal J, Chen Z, et al (2021), JAMA Network Open vol 4, no 12, December 2021, e2138414

Importance: Women with disabilities have a higher risk of preterm birth, gestational diabetes, preeclampsia, and cesarean delivery; however, their risk of other obstetric interventions, adverse maternal outcomes, and clinical indications for increased cesarean delivery is unclear.

Objective: To evaluate risk of a range of obstetric interventions and adverse maternal outcomes, including severe maternal morbidities (SMM) and mortality, among women with and without disabilities.

Design, Setting, and Participants: The Consortium on Safe Labor was a retrospective cohort that included comprehensive medical chart review for deliveries between January 2002 and January 2008. Data were collected from 12 clinical sites, which included 19 hospitals across the United States. This secondary analysis was conducted in February to July 2021.

Exposures: Using International Classification of Diseases, Ninth Revision, codes and a validated algorithm to define disability, participants were classified as having physical, intellectual, sensory, or any disability, and compared with women with no documented disability.

Main Outcomes and Measures: The relative risk (RR) of 23 obstetric interventions and adverse maternal outcomes, including SMM and mortality, was evaluated.

Results: Of the 223 385 women in the study, 9206 (4.1%) were Asian or Pacific Islander, 50 235 (22.5%) were Black, 39 039 (17.5%) were Hispanic, and 110 443 (49.4%) were White, with a mean (SD) age of 27.6 (6.2) years. There were 2074 (0.9%) women with disability and 221 311 (99.1%) without. Among women with disabilities, 1733 (83.5%) were physical, 91 (4.4%) were intellectual, and 250 (12.1%) were sensory. Compared with women with no disability, women with disabilities had higher risk of gestational diabetes, placenta previa, premature rupture of membranes, preterm premature rupture of membranes, and postpartum fever as well as maternal death (adjusted relative risk [aRR], 11.19; 95% CI, 2.40-52.19) and individual SMMs: severe preeclampsia/eclampsia (aRR, 2.15; 95% CI, 1.80-2.56), hemorrhage (aRR, 1.27; 95% CI, 1.09-1.49), and fever (aRR, 1.32; 95% CI, 1.03-1.67), with the highest risk observed for thromboembolism (aRR, 6.08; 95% CI, 4.03-9.16), cardiovascular events (aRR, 4.02; 95% CI, 2.87-5.63), and infection (aRR, 2.69; 95% CI, 1.97-3.67). Women with any disability also had higher risk of interventions, including oxytocin augmentation, operative vaginal delivery, and cesarean delivery (aRR, 1.33; 95% CI, 1.25-1.42), with the cesarean indication less likely to be medically indicated (aRR, 0.79; 95% CI, 0.70-0.89). Risk of adverse outcomes and interventions remained consistent across disability categories.

Conclusions and Relevance: In this study, women with physical, intellectual, and sensory disability during pregnancy were at higher risk of adverse outcomes, including a broad range of SMM and maternal mortality. (Author)

Full URL: https://doi.org/10.1001/jamanetworkopen.2021.38414

2021-12115

Relationship building. Anon (2021), Midwives vol 24, November 2021, pp 34-35

The award-winning Vulnerable in Pregnancy service in Fife is offering wrap-around care for women with learning disabilities alongside other vulnerabilities. (Author)

2021-09133

A different approach. Lucas G, Douglass E, Daniels L (2021), Midwives vol 24, September 2021, pp 34-35

Geraldine Lucas and Emma Douglass of the University of the West of England and Lynsey Daniels at Devon Partnership NHS Trust discuss how to support women with learning disabilities through pregnancy. (Author)

2021-05632

Supporting the delivery of good maternity care for parents with learning disabilities. Cox A, Parsons T, Watkin S, et al (2021), Midwifery vol 102, November 2021, 103073

Background and objective

Despite directives to improve maternity care in general and to improve care for parents with learning disabilities, the experience of parents with learning disabilities is often poor and lacking reasonable adjustments to care. The objective of this study was to develop resources - in collaboration with keystakeholders - to support the workforce in delivering good maternity care to parents with learning disabilities.

Design

A two-phase mixed-methods study.

Participants

Phase 1: 16 key stakeholders (health and social care professionals, parents with learning disabilities and their informal supporters/carers) were interviewed to understand views of best practice and inform resource development. Phase 2: 20 healthcare professionals engaged with the resources and gave feedback via online survey or discussion group to further refine them.

Findings

Thematic analysis of key stakeholder interviews indicated that good maternity care for parents with learning disabilities requires a positive and proactive approach to identifying need; reasonable adjustments to communication and providing information; and professionals working together to support and enable parents.

Key conclusions

Health and social care professionals identified barriers to the delivery of good maternity care for parents with learning disabilities, including how to identify whether a parent has learning disabilities. Professionals in maternity services require additional resources to ensure parents' needs are recognised and they are provided with personalised preparation for parenthood and sufficient support.

Implications for practice

The Together Toolkit and Maternity Passport were coproduced to support the workforce to deliver good maternity care to parents with learning disabilities, these resources are free and accessible for use [https://www.surrey.ac.uk/research-projects/together-project-supporting-delivery-goodpractice-maternity-services-parents-learning-disabilities]. Further evaluation will explore acceptability and perceived impact of these resources in maternity services. (Author)

2021-04811

Learning Disability: Contraception [written answer]. House of Commons (2021), Hansard Written question 11656, 7 June 2021

Nick Gibb responds to a written question from Marsha de Cordova to the Secretary of State for Education, regarding what steps his Department is taking to improve access to contraception for people with learning disabilities as part of relationships and sex education. (JSM)

Full URL: https://questions-statements.parliament.uk/written-questions/detail/2021-06-07/11656

2021-03853

Birth outcomes affecting infants of mothers with intellectual and developmental disabilities. Rubenstein E, Ehrenthal DB, Mallinson DC, et al (2021), Paediatric and Perinatal Epidemiology vol 35, no 6, November 2021, pp 706-716

Background
Women with intellectual and developmental disabilities (IDD) face increased risk of adverse maternal pregnancy outcomes, yet less is known about infant outcomes.

Objectives
To examine birth outcomes of infants born to mothers with IDD and assess associations with demographics and IDD-type.

Methods
We used data from the Big Data for Little Kids project, which links Wisconsin birth records to Medicaid claims for live births covered by Medicaid from 2007 to 2016. We identified IDD using maternal prepregnancy Medicaid claims and ran Poisson regression (with a log link function) with robust variance clustered by mother to compare prevalence of outcomes between singleton births with and without mothers with IDD. We adjusted the associations for demographic factors and estimated prevalence ratios (PR) as the effect measure. We assessed outcomes by IDD-type (intellectual disability, genetic conditions, cerebral palsy, and autism spectrum disorder) to explore differences by categories of IDD.

Results
Of 267,395 infants, 1696 (0.6%) had mothers with IDD. A greater percentage of infants with mothers with IDD were born preterm (12.8% vs 7.8%; PR 1.64, 95% confidence interval [CI] 1.42, 1.89), small for gestational age (8.5% vs 5.4%; PR 1.42, 95% CI 1.25, 1.61), and died within 12 months of birth (3.2% vs 0.7%; PR 4.93, 95% CI 3.73, 6.43) compared to infants of mothers without IDD. Prevalence ratios were robust to adjustment for demographics factors. Estimates did not meaningfully differ when comparing different IDD-types.

Conclusions
A greater porportion of infants born to mothers with IDD who were covered by Medicaid had poor outcomes compared to other infants. Prevalence of poor infant outcomes was greater for mothers with IDD even after accounting for demographic differences. It is imperative to understand why infants of mothers with IDD are at greater risk so interventions and management can be developed. (Author)

2021-02204

Association of Preexisting Disability With Severe Maternal Morbidity or Mortality in Ontario, Canada. Brown HK, Ray JG, Chen S, et al (2021), JAMA Network Open vol 4, no 2, February 2021, e2034993

Importance Severe maternal morbidity and mortality are important indicators of maternal health. Pregnancy rates are increasing in women with disabilities, but their risk of severe maternal morbidity and mortality is unknown, despite their significant social and health disparities.

Objective To determine the risk of severe maternal morbidity or mortality among women with a physical, sensory, or intellectual/developmental disability compared with women without disabilities.

Design, Setting, and Participants This population-based cohort study used linked health administrative data in Ontario, Canada, from 2003 to 2018. The cohort included all singleton births to women with preexisting physical, sensory, and intellectual/developmental disabilities as well as with 2 disabilities or more compared with women without a disability. Data analysis was conducted from September 2019 to September 2020.

Exposures Disabilities were identified with published algorithms applied to diagnoses in 2 physician visits or more or at least 1 emergency department visit or hospitalization.

Main Outcomes and Measures Severe maternal morbidity (a validated composite of 40 diagnostic and procedural indicators) or all-cause maternal mortality, arising between conception and 42 days post partum. Relative risks were adjusted for maternal age, parity, income quintile, rurality, chronic medical conditions, mental illness, and substance use disorders.

Results The cohort comprised women with physical disabilities (144 972 women; mean [SD] age, 29.8 [5.6] years), sensory disabilities (45 259 women; mean [SD] age, 29.1 [6.0] years), intellectual/developmental disabilities (2227 women; mean [SD] age, 26.1 [6.4] years), and 2 or more disabilities (8883 women; mean [SD] age, 29.1 [6.1] years), and those without disabilities (1 601 363 women; mean [SD] age, 29.6 [5.4] years). The rate of severe maternal morbidity or death was 1.7% (27 242 women) in women without a disability. Compared with these women, the risk of severe maternal morbidity or death was higher in women with a physical disability (adjusted relative risk [aRR], 1.29; 95% CI, 1.25-1.34), a sensory disability (aRR, 1.14; 95% CI, 1.06-1.21), an intellectual/developmental disability (aRR, 1.57; 95% CI, 1.23-2.01), and 2 or more disabilities (aRR, 1.74; 95% CI, 1.55-1.95). Similar aRRs were observed for severe maternal morbidity or death arising in pregnancy, from birth to 42 days post partum, and from 43 to 365 days post partum. Women with disabilities were more likely than those without disabilities to experience multiple severe maternal morbidity indicators. The most prevalent indicators in all groups were intensive care unit admission, severe postpartum hemorrhage, puerperal sepsis, and severe preeclampsia.

Conclusions and Relevance In this study, women with a preexisting disability were more likely to experience severe maternal morbidity or mortality. Preconception and perinatal care provisions should be considered among women with a disability to mitigate the risk of these rare but serious outcomes.

Full URL: https://doi.org/10.1001/jamanetworkopen.2020.34993

20201012-20*

Postpartum Health Care Among Women With Intellectual and Developmental Disabilities. Clements KM, Mitra M, Zhang J, et al (2020), American Journal of Preventive Medicine vol 59, no 3, September 2020, pp 437-444

Introduction

Postpartum health care among women with intellectual and developmental disabilities has not been well studied. This study uses administrative claims to compare postpartum outpatient visits among women with and without intellectual and developmental disabilities.

Methods

Massachusetts All Payers Claims Database 2012-2015 was used to identify women with intellectual and developmental disabilities and a live birth during 2012-2014, matched by infant birth year to 3 women without intellectual and developmental disabilities. Women were followed up for 1 year after delivery. Analyses were conducted in 2019. Poisson regression compared guideline-concordant postpartum and other outpatient visits during the early (21-56 days after delivery) and late (57-365 days after delivery) periods. Types of nonpostpartum care visits were examined.

Results

Overall, 962 and 2,886 women with and without intellectual and developmental disabilities, respectively, comprised the sample. Among women with intellectual and developmental disabilities, 23.9% had a postpartum visit in the early and 33.3% in the late postpartum periods, compared with 25.2% and 32.1% of women without intellectual and developmental disabilities who had visits in the early and late postpartum periods, respectively (p=0.49, 0.59). Women with intellectual and developmental disabilities were more likely to have other outpatient visits than those without intellectual and developmental disabilities, both in the early (63.1% vs 40.3%, adjusted RR=1.42, 95% CI=1.28, 1.58, p<0.001) and late (94.2% vs 82.3%, RR=1.11, 95% CI=1.08, 1.14, p=0.008) postpartum periods. Ancillary services, home health services, and alcohol/drug-related visits were much more common among women with intellectual and developmental disabilities.

Conclusions

Women with intellectual and developmental disabilities are equally likely to receive guideline-concordant postpartum visits and more likely to have other outpatient visits than other women. Further research is needed to evaluate visit quality and identify best practices to support mothers with intellectual and developmental disabilities during the postpartum period. (Author)

Full URL: https://doi.org/10.1016/j.amepre.2020.03.011

20200824-25*

Preconception Health Characteristics of Women with Disabilities in Ontario: A Population-Based, Cross-Sectional Study. Tarasoff LA, Lunsky Y, Chen S, et al (2020), Journal of Women's Health vol 29, no 12, December 2020, pp 1564-1575

Background: There is growing recognition that preconception health, defined as the health of all reproductive-age individuals, impacts reproductive and perinatal outcomes. Although women with disabilities are becoming pregnant at increasing rates, little is known about their preconception health. Our objective was to describe the preconception health characteristics of women with physical, sensory, and intellectual/developmental disabilities and compare these characteristics with women without disabilities.

Materials and Methods: We conducted a population-based cross-sectional study of 15- to 44-year-old women with physical (n = 253,184), sensory (n = 93,170), intellectual/developmental (n = 8,986), and multiple disabilities (n = 29,868), and women without these disabilities (n = 2,307,822) using Ontario health administrative data (2017-2018). We described preconception health variables related to social determinants of health, physical health status, psychosocial well-being, history of assault, medication use, and continuity of primary care and compared women with and without disabilities in crude and age-standardized analyses, with standardized differences >0.10 indicating clinically meaningful results.

Results: Women with physical, sensory, intellectual/developmental, and multiple disabilities had poorer preconception health than women without disabilities. Disparities were pronounced for physical health status, psychosocial well-being, use of potentially teratogenic medications, and history of assault. Of all groups, women with intellectual/developmental disabilities had the greatest disparities.

Conclusion: Further research is needed to identify contributors to poor preconception health among women with disabilities and to develop tailored preconception health interventions to meet their unique needs and experiences. (Author)

20200727-50

Show and tell. Morgan S (2020), Midwives vol 23, July 2020, pp 46-47

Sarah Morgan, Public Health Registrar for NHS England (London region), evaluates the PHE antenatal and newborn screening guides for women with learning disabilities. (Author)

20200722-79*

Pregnancy Outcomes Among U.S. Women With Intellectual and Developmental Disabilities. Parish SL, Mitra M, Son E, et al (2015), American Journal of Intellectual and Developmental Disabilities vol 120, no 5, September 2015, pp 433-443

The existing research on pregnancy outcomes for women with intellectual and developmental disabilities (IDD) is sparse. This study analyzed the 2010 Healthcare Cost and Utilization Project Nationwide Inpatient Sample and compared deliveries among women with IDD (n = 340) to the general obstetric population. Women with IDD had longer hospital stays and were more likely to have Caesarean deliveries in contrast to other women. Rates of adverse pregnancy outcomes were elevated for women with IDD across a range of measures, including early labor, preterm birth, and preeclampsia, and their infants were more likely to have low birth weight, even after adjusting for age, race, ethnicity, and insurance type. Targeted interventions are needed to address these deleterious outcomes. (Author)

Full URL: https://doi.org/10.1352/1944-7558-120.5.433

20200722-78*

Pregnancy outcomes among women with intellectual and developmental disabilities. Mitra M, Parish SL, Clements KM, et al (2015), American Journal of Preventive Medicine vol 48, no 3, March 2015, pp 300-308

Background: There is currently no population-based research on the maternal characteristics or birth outcomes of U.S. women with intellectual and developmental disabilities (IDDs). Findings from small-sample studies among non-U.S. women indicate that women with IDDs and their infants are at higher risk of adverse health outcomes.
Purpose: To describe the maternal characteristics and outcomes among deliveries to women with IDDs and compare them to women with diabetes and the general obstetric population.
Methods: Data from the 1998-2010 Massachusetts Pregnancy to Early Life Longitudinal database were analyzed between November 2013 and May 2014 to identify in-state deliveries to Massachusetts women with IDDs.
Results: Of the 916,032 deliveries in Massachusetts between 1998 and 2009, 703 (<0.1%) were to women with IDDs. Deliveries to women with IDDs were to those who were younger, less educated, more likely to be black and Hispanic, and less likely to be married. They were less likely to identify the father on the infant's birth certificate, more likely to smoke during pregnancy, and less likely to receive prenatal care during the first trimester compared to deliveries to women in the control groups (p<0.01). Deliveries to women with IDDs were associated with an increased risk of adverse outcomes, including preterm delivery, very low and low birth weight babies, and low Apgar scores.
Conclusions: Women with IDDs are at a heightened risk for adverse pregnancy outcomes. These findings highlight the need for a systematic investigation of the pregnancy-related risks, complications, costs, and outcomes of women with IDDs. (Author)
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20200623-44*

Antenatal and newborn screening: supporting women with learning disabilities. Public Health England (2020), London: PHE 22 June 2020

Information to support women with learning disabilities to access and understand antenatal and newborn screening. (Author)

Full URL: https://www.gov.uk/government/publications/annb-screening-supporting-women-with-learning-disabilities

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20200617-14*

Abortion: Northern Ireland [written answer]. House of Commons (2020), Hansard Written question 58833, 11 June 2020

Mr Robin Walker responds to a written question from Carla Lockhart to the Secretary of State for Northern Ireland, with reference to the Government consultation, A new legal framework for abortion services in Northern Ireland, published 4 November 2019, what estimate he has made of the number of submissions from (a) disability organisations and (b) people who identified as disabled. (JSM)

Full URL: https://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2020-06-11/58833/

20200617-11*

Abortion: Northern Ireland [written answer]. House of Commons (2020), Hansard Written question 58834, 11 June 2020

Mr Robin Walker responds to a written question from Carla Lockhart to the Secretary of State for Northern Ireland, with reference to the Government consultation entitled 'A new legal framework for abortion services in Northern Ireland', published 4 November 2019, what estimate he has made of the number of submissions from (a) disability organisations based in Northern Ireland and (b) individuals residing in Northern Ireland who identified as disabled. (Author, edited)

Full URL: https://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2020-06-11/58834/

20200615-26*

Defining vulnerability in European pregnant women, a Delphi study. Scheele J, van der Vliet-Torij HWH, Wingelaar-Loomans EM, et al (2020), Midwifery vol 86, July 2020, 102708

Objective

Vulnerability among pregnant women is an important and complex theme in the everyday practice of midwives. Exchanging knowledge and best practices about vulnerability between midwives in Europe can contribute to improving the knowledge and skills of midwives and as a result improve the care for vulnerable pregnant women. We therefore start a consortium with midwives, midwifery teachers, researchers and students from organizations of seven European cities with the aim to exchange knowledge and best practices concerning vulnerable pregnant women between midwives. To be able to effectively exchange knowledge and best practices, our consortium started with this study focuses on establishing a mutual definition of vulnerable pregnant women. Therefore, the aim of this study is to develop a mutual definition of vulnerable pregnant women and to identify aspects related to vulnerability.

Design

Delphi study with four rounds: (1) gathering existing knowledge from literature and definitions used by partners of the consortium, (2) and (3) two survey rounds and (4) an in-person consensus meeting.

Setting

Consortium of midwives, midwifery teachers, researchers and students from Antwerp (Belgium), Ghent (Belgium), Turku (Finland), Milan (Italy), Piła (Poland), Lisbon (Portugal) and Rotterdam (The Netherlands)

Participants

We included all consortium members in the Delphi study.

Findings

Various aspects related to vulnerability and appropriate definitions were identified during the Delphi rounds. Consensus about the aspects related to vulnerability and the definition of vulnerable pregnant women was reached during the final consensus meeting. A vulnerable pregnant woman was defined as a woman who is threatened by physical, psychological, cognitive and/or social risk factors in combination with lack of adequate support and/or adequate coping skills.

Key conclusion

We reached consensus about a mutual definition of vulnerable pregnant women and aspects related to vulnerability within this consortium. The Delphi approach led to interesting discussions and was a valuable method to define the concept of vulnerable pregnant women within our project .

Implications for practice

In order to accomplish a project that aimed to improve care for vulnerable pregnant women it was important to first identify the population of vulnerable pregnant women with a mutual definition. (Author) [Erratum: Midwifery, vol 128, January 2024, 103872. https://doi.org/10.1016/j.midw.2023.103872]

20200526-24*

Supporting women facing multiple disadvantage during COVID-19: Guidance for midwives. Bicknell T, Birth Companions (2020), London: Birth Companions 2020. 4 pages

This guidance for midwives working with women experiencing multiple disadvantage during the COVID-19 pandemic has been developed by Birth Companions and Consultant Midwife Tamsin Bicknell. It draws on recent research to offer insights into women's needs, and key considerations for their maternity care in these challenging times. (Author)

Full URL: https://hubble-live-assets.s3.amazonaws.com/birth-companions/redactor2_assets/files/253/Supporting_women_facing_multiple_disadvantage_during_COVID-19_Guidance_for_midwives_FINAL.pdf

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20200422-44*

Disability and Pregnancy: A Cross-Federal Agency Collaboration to Collect Population-Based Data About Experiences Around the Time of Pregnancy. D'Angelo DV, Cernich A, Harrison L, et al (2020), Journal of Women's Health vol 29, no 3, March 2020, pp 291-296

Many reproductive-aged women with a disability can achieve successful healthy pregnancies; however, they may face challenges accessing prenatal and postpartum care and finding providers who are knowledgeable about their specific condition. Depending on the nature of the disability, some women may also be at increased risk for adverse maternal and infant outcomes such as pre-eclampsia, infection, anemia, primary cesarean delivery, or preterm birth. Population-based data are needed to better understand the pregnancy and postpartum experiences of women living with disability. The National Institutes of Health and the Centers for Disease Control and Prevention (CDC) collaborated to address these data gaps by leveraging CDC's Pregnancy Risk Assessment Monitoring System (PRAMS) to gather information about disability among women who have had a recent live birth. Data collection began in 2019. Information gathered through PRAMS can be used to guide the development of clinical practices guidelines, intervention programs, and other initiatives of federal, state, and local agencies to improve services and the health of women of reproductive age living with disability. (Author)

20200309-1*

Pregnancy Intendedness by Maternal Disability Status and Type in the United States. Horner-Johnson W, Dissanayake M, Wu JP, et al (2020), Perspectives on Sexual and Reproductive Health vol 52, no 1, March 2020, pp 31-38

CONTEXT

Societal views about sexuality and parenting among people with disabilities may limit these individuals' access to sex education and the full range of reproductive health services, and put them at increased risk for -unintended pregnancies. To date, however, no national population-based studies have examined pregnancy -intendedness among U.S. women with disabilities.

METHODS

Cross-sectional analyses of data from the 2011-2013 and 2013-2015 waves of the National Survey of Family Growth were conducted; the sample included 5,861 pregnancies reported by 3,089 women. The proportion of pregnancies described as unintended was calculated for women with any type of disability, women with each of five types of disabilities and women with no disabilities. Multivariate logistic regression analyses were conducted to examine the relationship of disability status and type with pregnancy intendedness while adjusting for covariates.

RESULTS

A higher proportion of pregnancies were unintended among women with disabilities than among women without disabilities (53% vs. 36%). Women with independent living disability had the highest proportion of unintended pregnancies (62%). In regression analyses, the odds that a pregnancy was unintended were greater among women with any type of disability than among women without disabilities (odds ratio, 1.4), and were also elevated among women with hearing disability, cognitive disability or independent living disability (1.5-1.9).

CONCLUSIONS

Further research is needed to understand differences in unintended pregnancy by type and extent of disability. People with disabilities should be fully included in sex education, and their routine care should incorporate discussion of reproductive planning. (Author)

20200221-73

Rates of recognized pregnancy in women with disabilities in Ontario, Canada. Brown HK, Chen S, Guttmann A, et al (2020), American Journal of Obstetrics & Gynecology (AJOG) vol 222, no 2, February 2020, pp 189-192

The authors present a population-based study on the rates of recognised pregnancy among women with and without physical, sensory or intellectual disabilities. (5 references) (LDO)

20200124-40*

Miscarriage Occurrence and Prevention Efforts by Disability Status and Type in the United States. Dissanayake MV, Darney BG, Caughey AB, et al (2020), Journal of Women's Health vol 29, no 3, March 2020, pp 345-352

Background: Very little is known about early pregnancy loss in women with disabilities. To address this gap, we analyzed nationally representative data on miscarriage and receipt of care focused on miscarriage prevention among women with and without disabilities.

Materials and Methods: We used 2011-2015 National Survey of Family Growth data on women with at least one completed pregnancy within the past 5 years. Bivariate and multivariate analyses assessed the association of six disability categories (any, hearing, vision, cognitive, physical, independent living) with miscarriage occurrence and receipt of services intended to prevent miscarriage.

Results: Our analytic sample included 3,843 women with 5,776 completed pregnancies within the past 5 years. Overall, 31.63% of women with disabilities and 21.83% of women without disabilities had had a miscarriage within the past 5 years. Compared to women without disabilities, women with any, cognitive, physical, and independent living disability had higher adjusted odds of experiencing miscarriage (any disability aOR = 1.65 [95% CI: 1.21-2.25]). These women also had higher odds of receiving services to prevent miscarriage compared with women without disabilities (any disability aOR = 1.71 [95% CI: 1.20-2.45]). Among women who received services, higher proportions of women with any, vision, physical, or independent living disability received recommendations for bed rest (e.g., 65.007% of women with independent living disability vs. 33.98% of women without disability, p = 0.018).

Conclusions: In a representative sample of U.S. women, we found significant differences in the odds of miscarriage and in receipt of care to prevent miscarriage between women with and without disabilities. Further research is needed to understand why women with disabilities are more likely to experience a miscarriage. Such research is important for informing care recommendations. (32 references) (Author)

Full URL: https://doi.org/10.1089/jwh.2019.7880

20200115-9*

A comparative study of autistic and non-autistic women's experience of motherhood. Pohl AL, Crockford SK, Blakemore M, et al (2020), Molecular Autism vol 11, no 3, 6 January 2020

Background

Autism is a lifelong neurodevelopmental difference and disability, yet there is limited research examining parenting in autistic mothers.

Objective

To explore autistic mothers' experience of the perinatal period and parenthood. This includes pregnancy, childbirth, the postpartum period, self-perception of parenting strengths and weaknesses, communication with professionals in relation to one's child, mental health difficulties and the social experience of motherhood. It also includes disclosing one's diagnosis of autism in parenting contexts.

Methods

We used a community-based participatory research model, and recruited an advisory panel, with whom we co-developed an anonymous, online survey for autistic mothers. The online survey was completed by autistic and non-autistic mothers, and we compared their responses using Chi-squared analysis.

Sample

Autistic mothers (n = 355), and non-autistic mothers (n = 132), each of whom had at least one autistic child, were included in our final analysis.

Results

There were differences in education, gender identity and age of mother at birth of first child. Autistic mothers were more likely to have experienced additional psychiatric conditions, including pre- or post-partum depression, and reported greater difficulties in areas such as multi-tasking, coping with domestic responsibilities and creating social opportunities for their child. They were also more likely to report feeling misunderstood by professionals, and reported greater anxiety, higher rates of selective mutism, and not knowing which details were appropriate to share with professionals. They were also more likely to find motherhood an isolating experience, to worry about others judging their parenting, or feel unable to turn to others for support in parenting. However, despite these challenges, autistic mothers were able to act in the best interest of their child, putting their child's needs first.

Conclusions

Autistic mothers face unique challenges and the stigma associated with autism may further exacerbate communication difficulties. Greater understanding and acceptance amongst individuals who interact with autistic mothers is needed, and autistic mothers would benefit from additional and better-tailored support. (38 references) (Author)

Full URL: https://doi.org/10.1186/s13229-019-0304-2

20190925-45

People with learning disabilities accessing maternity services. Vernon S (2019), British Journal of Midwifery vol 27, no 9, September 2019, pp 589-592

From September 2018-June 2019, I was fortunate enough to undertake a research internship with the National Institute for Health Research (NIHR). My chosen topic was 'people with learning disabilities accessing maternity services'. This was because, through 19 years of clinical practice, I identified an increasing number of women and families with learning disabilities presenting for care in my Trust, but found no specific mention of learning disabilities in the National Institute for Health and Care Excellence (NICE) (2019) guidelines, nor a standard definition within which to work.

This led me to reflect on my experience and how midwives can assist women and families with learning disabilities. This reflection has been guided by Gibbs (1988). (Author)

20190507-64*

Maternity experiences of mothers with multiple disadvantages in England: A qualitative study. Mcleish J, Redshaw M (2019), Women and Birth: Journal of the Australian College of Midwives vol 32, no 2, April 2019, pp 178-184

Background

Disadvantaged mothers and their babies are at increased risk of poor perinatal outcomes and have less positive experiences of maternity care.

Aim

To explore the maternity care experiences of mothers with multiple disadvantages.

Methods

A qualitative descriptive study based on semi-structured interviews with 40 mothers with multiple disadvantages, using thematic analysis.

Findings

Four themes emerged: 'A confusing and frightening time', 'Longing to be respected as an individual', 'The importance of choice and control', and 'Needing trust to feel safe'. Mothers brought feelings of powerlessness and low self-esteem to their encounters with maternity professionals, which could be significantly worsened by disrespectful care. They needed support to navigate the complex maternity system. Positive experiences were much more likely where the mother had received continuity of care from a specialist midwife or small team.

Discussion and conclusion

Mothers with multiple disadvantages value being treated as an individual, making informed choices, and feeling safe, but they may lack the confidence to ask questions or challenge disrespectful treatment. Training and supervision should enable maternity professionals to understand how confusing maternity care can be to very disadvantaged mothers. It should emphasise the need to provide accessible and empowering information and guidance to enable all mothers to make choices and understand the system. Leaders of maternity services need to do more to challenge negative staff attitudes and ensure that that all mothers are treated at all times with kindness, respect and dignity. Specialist midwives can deliver a high quality service to mothers experiencing multiple disadvantages. (47 references) (Author)

Full URL: https://doi.org/10.1016/j.wombi.2018.05.009

20190215-7*

Differences in prenatal care by presence and type of maternal disability. Horner-Johnson W, Biel FM, Caughey AB, et al (2019), American Journal of Preventive Medicine vol 56, no 3, March 2019, pp 376-382

Introduction

Prior studies have found that women with disabilities are less likely to receive adequate prenatal care than women without disabilities. However, little is known about differences in patterns of prenatal care by type of disability. Therefore, this study examined timing and frequency of prenatal care among women with physical, sensory, or intellectual/developmental disabilities compared with women without disabilities.

Methods

This was a retrospective cohort study using linked maternal and infant hospital discharge and birth certificate data for all births in California in 2000-2012 (N=6,745,201). Analyses were conducted in 2017-2018. Modified Poisson regression analyses compared women with each type of disability with women without disabilities on trimester of prenatal care initiation and number of prenatal care visits.

Results

Women with intellectual/developmental disabilities or with limited hearing had significantly higher RR of delaying prenatal care initiation until the second or third trimester (intellectual/developmental disabilities: adjusted RR=1.21, 95% CI=1.09, 1.33; hearing: adjusted RR=1.11, 95% CI=1.02, 1.21), whereas women with physical disabilities and limited vision had lower risk of delaying care (physical: adjusted RR=0.91, 95% CI=0.88, 0.94; vision: adjusted RR=0.85, 95% CI=0.73, 0.99). Women with limited hearing or vision or intellectual/developmental disabilities had higher risk of receiving fewer prenatal visits than recommended, compared with women without disabilities. Women with physical disabilities or intellectual/developmental disabilities had higher RR of receiving more than the typical number of visits.

Conclusions

There were key differences in prenatal care utilization by disability type, reflective of particularly pronounced disparities for women with intellectual/developmental disabilities and women with limited hearing. Delays in receipt of prenatal care and low numbers of prenatal care visits may contribute to the poorer birth outcomes that have been observed previously in these groups. Targeted interventions are needed to improve uptake of prenatal care in these vulnerable populations. (38 references) (Author)

Full URL: https://doi.org/10.1016/j.amepre.2018.10.021

20190215-20*

In pursuit of intimacy: disability stigma, womanhood and intimate partnerships in South Africa. Van der Heijden I, Harries J, Abrahams N (2019), Culture, Health & Sexuality vol 21, no 3, March 2019, pp 338-351

Notions of womanhood inculcate naturalised ideologies of femininity, sexuality, motherhood and caregiving. The paper asks how disability stigma intersects with womanhood to characterise intimate partnerships in South Africa. In-depth interviews with 30 women with a range of disabilities were conducted in informal settlements in Cape Town. Findings suggest that disability stigma may hamper attainment of normative womanhood and sexual relationships for women with disabilities in South Africa. Limited opportunities to meet potential partners, hegemonic gender expectations and restricted sexual and physical contact shape their intimate partnerships. However, women with disabilities also challenge ableist constructs of normalcy and discredit negative images of disabled womanhood. Because of this, theoretical models of intimate partner violence should consider the influence of disability on constructions of sexuality and norms in intimate partnerships. Building on women with disabilities' stigma-avoidance strategies will help facilitate better relationship outcomes. Social norms interventions with broader society, communities, women with disabilities and their partners, family and carers can help destabilise assumptions that women with disabilities are unable to have long-lasting and fulfilling sexual and intimate partnerships. Moreover, accessible and relevant sexuality education and information on relationships, intimate partner violence, maternal and sexual and reproductive health care can ensure healthy and safe intimate partnerships for women with disabilities. (35 references) (Author)

20190207-6

The loaded die: Parenting with learning disabilities and the role of the midwife in Scotland. Corrigan A (2019), British Journal of Midwifery vol 27, no 1, January 2019, pp 49-53

An increasing number of women with learning disabilities are becoming parents, and have a legal right to do so free from discrimination. By discussing the evidence, this article argues that the health and social care systems of the UK have been historically poor at supporting successful parenting for people with learning disabilities. It discusses the legislative and policy landscape in Scotland that should be changing this situation and considers the role of the midwife within this. It identifies the need for improved training and support for midwives and recognition of the time investment required to provide care for women with learning disabilities if they are avoid a loaded die against their successful parenting from the outset. (Author)

20181203-30*

Pregnancy outcomes in women with autism: a nationwide population-based cohort study. Sundelin HEK, Stephansson O, Hultman CM, et al (2018), Clinical Epidemiology vol 2018, no 10, 30 November 2018, pp 1817-1826

Background: The consequences of autism in pregnancy outcomes have not been explored before, although it is of crucial importance because of the frequent comorbidities and medication in this group of women.
Objectives: To estimate the risk of adverse pregnancy outcomes in women diagnosed with autism.
Design: Nationwide population-based cohort study.
Setting: Sweden.
Participants: Singleton births identified in the Swedish Medical Birth Registry, 2006-2014. A total of 2,198 births to women diagnosed with autism registered in the Swedish National Patient Registry were compared to 877,742 singleton births to women without such a diagnosis.
Main outcome and measures: Preterm delivery. Secondary measures were cesarean delivery (emergency and elective), Apgar score <7 at 5 minutes, small for gestational age, large for gestational age, stillbirth, gestational diabetes, and preeclampsia. ORs were calculated through logistic regression, adjusted for maternal age at delivery, maternal country of birth, smoking, maternal body mass index, parity, calendar year of birth, and psychotropic and antiepileptic medication during pregnancy.
Results: Women with autism were at increased risk of preterm birth (OR=1.30; 95% CI=1.10-1.54), especially medically indicated preterm birth (OR=1.41; 95% CI=1.08-1.82), but not with spontaneous preterm birth. Maternal autism was also associated with an increased risk of elective cesarean delivery (OR=1.44; 95% CI=1.25-1.66) and preeclampsia (OR=1.34; 95% CI=1.08-1.66), but not with emergency cesarean delivery, low Apgar score (<7), large for gestational age, gestational diabetes, and stillbirth. In women with medication during pregnancy, there was no increased risk of adverse pregnancy outcome except for induction of delivery (OR=1.33; 95% CI=1.14-1.55).
Conclusion and relevance: Maternal autism is associated with preterm birth, likely due to an increased frequency of medically indicated preterm births, but also with other adverse pregnancy outcomes, suggesting a need for extra surveillance during prenatal care. (Author)

Full URL: https://doi.org/10.2147/CLEP.S176910

20181113-90*

Contraceptive Provision to Postpartum Women With Intellectual and Developmental Disabilities: A Population-Based Cohort Study. Brown HK, Kirkham YA, Lunsky Y, et al (2018), Perspectives on Sexual and Reproductive Health vol 50, no 3, September 2018, pp 93-99

CONTEXT
Women with intellectual and developmental disabilities who experience pregnancy, like all women, require postpartum care that supports their contraceptive knowledge and decision making. Yet, little is known about the postpartum contraceptive care these women receive, or how it compares with care given to other women.
METHODS
A population-based study using linked health and social services administrative data examined provision of postpartum contraceptive care to women who had a live birth in Ontario, Canada, in 2002-2014 and were beneficiaries of Ontario's publicly funded drug plan. Modified Poisson regression was used to compare care between 1,181 women with and 36,259 women without intellectual and developmental disabilities. Outcomes were provision of any nonbarrier contraceptive in the year following the birth and type of method provided.
RESULTS
In the first year postpartum, women with intellectual and developmental disabilities were provided with contraceptives at a higher rate than were other women (relative risk 1.3); the difference was significant for both nonsurgical and surgical methods (1.2 and 1.8, respectively). The higher rate of nonsurgical contraceptive provision was explained by provision of injectables (1.9); there were no differences for pills or IUDs.
CONCLUSION
Nonbarrier contraceptives may be the most appropriate methods for some women with intellectual and developmental disabilities. However, future research should investigate why women with such disabilities are more likely than others to receive injectable contraceptives, which have possible negative side effects, and surgical contraception, which is irreversible. Research also should investigate how these women perceive their participation in contraceptive decision making. (Author)

20180821-36

Enhancing effective communication among non-verbal patients. Baddley D (2018), Pediatric Nursing vol 44, no 3, May/June 2018, pp 144-146

Examines ways in which caregivers can facilitate effective communication with vulnerable and non-verbal patients and their families. (8 references) (MB)

20180502-34*

To what extent are midwives adapting antenatal information for pregnant women with intellectual disabilities? A survey of NHS trusts in England. Homeyard CE, Patelarou E (2018), Public Health vol 158, May 2018, pp 25-30

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. (33 references) (Author)

20180329-4*

Social Security Benefits: Pregnancy [written answer]. House of Commons (2018), Hansard Written question 134117, 23 March 2018

Sarah Newton responds to a written question asked by Danielle Rowley to the Secretary of State for Work and Pensions, asking whether her Department has any specific policies on personal independence payment and disability living allowance assessments for pregnant women. (MB)

20180208-43*

Disparities in Adverse Preconception Risk Factors Between Women with and Without Disabilities. Mitra M, Clements KM, Zhang J, et al (2016), Maternal and Child Health Journal vol 20, no 3, March 2016, pp 507-515

Objective The objective of this study was to compare the prevalence of select preconception health indicators among women with and without disabilities. Methods 2010 Behavioral Risk Factor Surveillance System data were used to estimate the prevalence of health behaviors, health status indicators, and preventive health care among non-pregnant women ages 18-44 years with (N = 8370) and without (N = 48,036) disabilities. Crude percentages were compared with Chi square statistics. Multivariable logistic regressions adjusted for socio-demographic factors. Results Women with disabilities were more likely than women without disabilities to currently smoke (30.5 vs. 14.5 %, $p < 0.0001$) and less likely to exercise in the past month (67.1 vs. 79.8 %, $p < 0.0001$). Heavy drinking was similar in the two groups (4.4 vs. 4.5 %, $p = 0.9$). Health status indicators were worse among women with disabilities, with 35.0 % reporting fair/poor health and 12.4 % reporting diabetes, compared with 6.7 and 5.6 %, respectively, among women with no disabilities ($p < 0.0001$ for both). Frequent mental distress, obesity, asthma, and lack of emotional support were also higher among women with disabilities compared with their non-disabled counterparts. Women with disabilities were more likely to receive some types of preventive care, (HIV), but less likely to receive others (recent dental cleaning, routine checkup). Disparities in health behaviors and health status indicators between the two groups remained after adjusting for socio-demographic factors. ConclusionWomen with disabilities at reproductive age are more vulnerable to risk factors associated with adverse pregnancy outcomes compared to their counterparts without disabilities. Our findings highlight the need for preconception health care for women with disabilities. (58 references) (Author)

20171128-4*

Maternal and child screening programmes launch easy read information. Public Health Wales (2017), Public Health Wales 27 November 2017

News item reporting that Public Health Wales's Maternal and Child Screening Programmes have launched a new series of easy-to-read information leaflets aimed at people with a learning disability. (MB)

Full URL: http://www.wales.nhs.uk/sitesplus/888/news/46836

20170831-136*

Fertility Desires and Intentions Among U.S. Women by Disability Status: Findings from the 2011-2013 National Survey of Family Growth. Bloom TL, Mosher W, Alhusen J, et al (2017), Maternal and Child Health Journal vol 21, no 8, August 2017, pp 1606-1615

Objectives We compared fertility desires and intentions among women with disabilities and women without disabilities in the United States, using a new evidence-based measure of disability.

Methods We analyzed data from a sample of 5601 US women 15-44 years of age in the 2011-2013 National Survey of Family Growth. The data were analyzed via cross-tabulation and logistic regression. We classified women into those with a disability and those without a disability.

Results Women with disabilities were about as likely to want a baby (61%) as women without disabilities (60%). But only 43% of women with disabilities intended to have a baby in the future, compared with 50% of women without disabilities. Thus, the difference between the percent who want a baby and the percent who intend to have one was larger for disabled women. Women with disabilities were also less certain of their fertility intentions. Multivariate analysis shows that having a disability lowers the odds of intending another birth, after controlling for several other determinants of fertility intentions.

Conclusions for Practice All women, regardless of disability status, desired more children than they actually planned to have, but the gap was larger for most groups of women with disabilities than for non-disabled women. Given the sample sizes available in this analysis, future research should use more detailed classifications of disability, however, we have shown that women living with disabilities constitute large populations with unexplored family planning needs. (Author)

20170727-93*

Healthcare provider's attitude towards disability and experience of women with disabilities in the use of maternal healthcare service in rural Nepal. Devkota HR, Murray E, Kett M, et al (2017), Reproductive Health vol 14, no 79, 29 June 2017

Background

Women with disabilities are less likely to receive maternal healthcare services compared to women without disabilities. While few studies have reviewed healthcare experience of women with disabilities, no studies have been conducted to understand provider's attitude towards disability in Nepal, yet the attitude and behaviour of healthcare providers may have a significant influence on aspects of care and the use of service by women with disabilities. This study examines healthcare provider's attitudes towards disability and explores the experience of women with disabilities in maternal healthcare service utilization during pregnancy and childbirth.

Method

The study used mixed method approach. An attitude survey was conducted among 396 healthcare providers currently working in public health facilities in Rupandehi district of Nepal. For additional insight, eighteen in-depth interviews with women with disabilities who used maternal healthcare services in a healthcare facility within the study district in their last pregnancy were undertaken. The Attitude Towards Disabled Persons (ATDP) scale score was used to measure the attitudes of healthcare providers. For quantitative data, univariate and multivariate analysis using ANOVA was used to understand the association between outcome and independent variables and qualitative analysis generated and described themes.

Results

Mean ATDP score among healthcare providers (78.52; SD = 14.75), was low compared to the normative score of 100 or higher. Nurses/auxiliary nurse midwives obtained the highest mean score (85.59, SD = 13.45), followed by general clinical health workers (Mean score = 82.64, SD 15.10). The lowest score was obtained by Female Community Health Volunteers (FCHV) (Score = 73.75, SD = 13.40) ($P < 0.001$). Younger providers were more positive compared to older age groups ($P < 0.001$). Similarly, providers working in urban health facilities compared to those working in rural health facilities, and non-Dalit providers compared to Dalit providers reported more positive attitudes towards disability ($P < 0.05$). However, there were no significant differences in ATDP mean scores between those who had or had not previously provided services for women with disabilities. The mean score difference between those who received disability training and who did not was also found statistically insignificant ($P > 0.05$). This may reflect the small number of individuals, who have had training on disability thus far, or the nature or quality of the training currently available.

The majority of qualitative interview participants perceived providers to have the negative attitude with poor knowledge, skills and preparation for providing care to persons with disabilities. Few participants perceived the providers as kind, respectful, caring or helpful.

Conclusion

Overall, provider's attitude towards disability was found to be negative with poor knowledge and skills about providing services. This may have adversely impact maternal healthcare service utilization by women with disabilities. More organized, effective training for healthcare providers is required through on-going mainstream efforts to develop favorable attitudes towards disability. Further research on this subject is also needed. (43 references) (Author) [Please note: BMC initially publishes articles in a provisional format. If there is a note on the document to indicate that it is still provisional, it may undergo minor changes]

Full URL: https://reproductive-health-journal.biomedcentral.com/articles/10.1186/s12978-017-0330-5

20170721-10*

Access and quality of maternity care for disabled women during pregnancy, birth and the postnatal period in England: data from a national survey. Malouf R, Henderson J, Redshaw M (2017), BMJ Open vol 7, no 7, July 2017, e016757

Objectives More disabled women are becoming mothers, and yet, their care is rarely the focus of quantitative research. This study aimed to investigate access and quality of maternity care for women with differing disabilities.
Design Secondary analysis was conducted on data from a 2015 national survey of women's experience of maternity care. Descriptive and adjusted analyses were undertaken for five disability groups: physical disability, sensory impairment, mental health disability, learning disability and multiple disability, and comparisons were made with the responses of non-disabled women.
Setting Survey data were collected on women's experience of primary and secondary care in all trusts providing maternity care in England.
Participants Women who had given birth 3‰months previously, among whom were groups self-identifying with different types of disability. Exclusions were limited to women whose baby had died and those who were younger than 16 years at the time of the recent birth.
Results Overall, 20‰094 women completed and returned the survey; 1958 women (9.5%) self-identified as having a disability. The findings indicate some gaps in maternity care provision for these women relating to interpersonal aspects of care: communication, feeling listened to and supported, involvement in decision making, having a trusted and respected relationship with clinical staff. Women from all disability groups wanted more postnatal contacts and help with infant feeding.
Conclusion While access to care was generally satisfactory for disabled women, women's emotional well-being and support during pregnancy and beyond is an area that is in need of improvement. Specific areas identified included disseminating information effectively, ensuring appropriate communication and understanding, and supporting womenâ€™s sense of control to build trusting relationships with healthcare providers. (30 references) (Author)

Full URL: http://bmjopen.bmj.com/content/7/7/e016757

20170526-27*

Postpartum Acute Care Utilization Among Women with Intellectual and Developmental Disabilities. Brown HK, Cobigo V, Lunsky Y, et al (2017), Journal of Women's Health vol 26, no 4, April 2017, pp 329-337

BACKGROUND:
Women with intellectual and developmental disabilities have high rates of pregnancy complications. However, their postpartum health is largely unknown. We compared risks for postpartum hospital admissions and emergency department visits among women with and without intellectual and developmental disabilities.
METHODS:
We conducted a population-based study using linked Ontario (Canada) health and social services administrative data to identify singleton live births to women with (N = 3,803) and without intellectual and developmental disabilities (N = 378,313) (2002-2012). Outcomes were hospital admissions and emergency department visits in the 42 days following delivery discharge. We classified these as medical or psychiatric depending on the recorded primary discharge diagnosis.
RESULTS:
Women with intellectual and developmental disabilities, compared to those without, had increased risk for postpartum hospital admissions overall (2.4% vs. 1.2%; adjusted hazard ratios [aHR]: 1.76, 95% confidence interval [CI]: 1.43-2.17) and for psychiatric reasons (0.8% vs. 0.1%; aHR: 10.46, 95% CI: 6.96-15.70), but not for medical reasons. They also had increased risk for postpartum emergency department visits overall (16.6% vs. 7.9%; aHR: 1.85, 95% CI: 1.71-2.01) and for both medical (15.8% vs. 7.8%; aHR: 1.80, 95% CI: 1.66-1.96) and psychiatric reasons (1.3% vs. 0.1%; aHR: 5.66, 95% CI: 4.17-7.69).
CONCLUSIONS:
High rates of postpartum hospital admissions and emergency department visits among women with intellectual and developmental disabilities demonstrate that this group may be vulnerable to acute complications or inadequate preventive care after childbirth. Providing enhanced health services during the postpartum period, in the form of longer or more frequent visits or specialized supports, could optimize their outcomes following delivery. (Author)

20170518-37*

Postpartum Health of Women with Intellectual and Developmental Disabilities: A Call to Action. Mitra M (2017), Journal of Women's Health vol 26, no 4, April 2017, pp 303-304

Comments on a paper published in the same issue of the journal [1] examining the risks of postnatal medical and psychiatric hospital admissions and A&E visits in women with intellectual and developmental disabilities compared with women without such disabilities. 1. Brown HK; Cobigo V; Lunsky Y; et al (2017). Journal of Women's Health, vol 26, no 4, April 2017, pp 329-337. (22 references) (MB)

Full URL: http://online.liebertpub.com/doi/pdfplus/10.1089/jwh.2017.6382

20170511-23#*

Mellow futures: a facilitator's perspective. O'Neill K (2017), International Journal of Birth and Parent Education vol 4, no 3, Spring 2017, pp 33-34

A Mellow Futures practitioner describes how the combination of a safe group environment, strengths-based feedback, encouragement from peers and the reinforcement of learning and skills at home, enable mums with learning difficulties to lead their lives and to parent as independently as possible. (Author)

20170511-20

Mellow futures: an adapted perinatal programme for parents with learning difficulties and disabilities. Tarleton B, Puckering C (2017), International Journal of Birth and Parent Education vol 4, no 3, Spring 2017, pp 29-32

Mellow Futures is a programme for parents with learning difficulties and disabilities adapted from the Mellow Bumps and Babies programmes with the addition of a mentor to support the mothers in transferring learning to their home environment. The evaluation of the pilot programmes (Tarleton & Turner 2016; 2015) found that mothers and the professionals who referred the mothers, recognised increases in maternal confidence, social connection and parenting skills. The level of concern regarding the welfare of the babies was also reduced in the majority of cases. (15 references) (Author)

20170327-24*

'We both just wanted to be normal parents': a qualitative study of the experience of maternity care for women with learning disability. Malouf R, Mcleish J, Ryan S, et al (2017), BMJ Open vol 7, no 3, March 2017, e015526

Background More women with learning disability (LD) are becoming mothers. Women with LD have rights to equal access to maternity care that meets their needs, however, many have poor pregnancy and birth outcomes compared to other women in the UK. Research is limited in this area.

Objectives The aim of the study was to explore the lived experiences of pregnancy, childbirth, prenatal and postnatal care and services received by this group of women in the UK, including their expressed information and support needs relating to maternity care.

Methods A qualitative study in which data were generated using in-depth semistructured interviews with learning disabled women who were pregnant or had given birth within the last 3 years in the UK; data were analysed using interpretative phenomenological analysis.

Results 9 women with varying levels of cognitive impairment took part. 4 super-ordinate themes were identified: 'I hate being treated differently', 'I find it harder to understand than other people', 'We've had to prove ourselves' and 'Make sure you've got very good support around you'. Subthemes included: 'Negative attitudes and denial of choice', 'Understanding of normal care', 'Written information' and 'Being judged by professionals'.

Conclusions With support from family and services, learning disabled women can become confident and successful parents. Maternity services should make reasonable adjustments when providing care to this group, including adapting to their individual communication and learning needs: allowing sufficient time in appointments, offering clear explanations of each aspect of care and sensitive support for autonomy and fully informed choice. Mothers who will be subject to a social care assessment of their parenting skills need clear information about the process, their choices and the level of skill they must demonstrate, as well as access to sufficient antenatal and postnatal support to give them the best possible chance of passing the assessment. (49 references) (Author)

Full URL: http://bmjopen.bmj.com/content/7/3/e015526

20170210-40*

Looking at your baby's hearing. An easy guide to screening tests for your new baby. Public Health England (2017), London: PHE February 2017. 9 pages

One of eight easy read guides explaining the screening tests offered during and after pregnancy for people with learning disabilities. (Publisher, edited)

Full URL: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/590113/STFYAYB_easy_read_baby_section_part_2_NHSP_Feb_2017_final.pdf

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20170210-38*

Looking at your baby's heart, eyes, hips and balls (testes). An easy guide to screening tests for your new baby. Public Health England (2017), London: PHE February 2017. 11 pages

One of eight easy read guides explaining the screening tests offered during and after pregnancy for people with learning disabilities. (Publisher, edited)

Full URL: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/590112/STFYAYB_easy_read_baby_section_part_1_Feb_2017_final.pdf

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20170210-37*

Screening for eye problems for pregnant women with diabetes. An easy guide to screening tests when you are pregnant. Public Health England (2017), London: PHE February 2017. 6 pages

One of eight easy read guides explaining the screening tests offered during and after pregnancy for people with learning disabilities. (Publisher, edited)

Full URL: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/590111/STFYAYB_easy_read_pregnancy_section_part_5_Feb_2017_final.pdf

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20170210-36*

Screening for problems with the baby's body. An easy guide to screening tests when you are pregnant. Public Health England (2017), London: PHE February 2017. 8 pages

One of eight easy read guides explaining the screening tests offered during and after pregnancy for people with learning disabilities. (Publisher, edited)

Full URL: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/590110/STFYAYB_easy_read_pregnancy_section_part_4_final.pdf

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20170210-33*

Screening for Down's syndrome, Edwards' syndrome and Patau's syndrome. An easy guide to screening tests when you are pregnant. Public Health England (2017), London: PHE February 2017. 10 pages

One of eight easy read guides explaining the screening tests offered during and after pregnancy for people with learning disabilities. (Publisher, edited)

Full URL: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/590109/STFYAYB_easy_read_pregnancy_section_part_3_Feb_2017_final.pdf

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20170210-27*

Screening for sickle cell disease and thalassaemia. An easy guide to screening tests when you are pregnant. Public Health England (2017), London: PHE February 2017. 13 pages

One of eight easy read guides explaining the screening tests offered during and after pregnancy for people with learning disabilities. (Publisher, edited)

Full URL: https://www.gov.uk/government/publications/screening-tests-for-you-and-your-baby-easy-guides

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20170210-25*

Screening for hepatitis B, HIV and syphilis: an easy guide to screening tests when you are pregnant [Last updated 3 June 2021]. Public Health England (2017), London: PHE February 2017. 9 pages

One of eight easy read guides explaining the screening tests offered during and after pregnancy for people with learning disabilities. (Publisher, edited)

Full URL: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/590107/STFYAYB_easy_read_pregnancy_section_1_IDPS_Feb_2017_final.pdf

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20161024-43*

Labour and delivery interventions in women with intellectual and developmental disabilities: a population-based cohort study.
Brown HK, Kirkham Y, Cobigo V, et al (2016), Journal of Epidemiology and Community Health vol 70, no 3, March 2016, pp 238-244

Background Our objectives were to: (1) examine the occurrence of labour induction, caesarean section, and operative vaginal delivery in women with intellectual and developmental disabilities compared to those without and (2) determine whether pre-pregnancy health conditions and pregnancy complications explain any elevated occurrence of these interventions.
Methods We conducted a population-based study using linked Ontario (Canada) administrative data. We identified deliveries to women with (N=3932) and without (N=382 774) intellectual and developmental disabilities (2002-2011). Modified Poisson regression was used to estimate adjusted relative risks (aRR) and 95% CIs for interventions, controlling for sociodemographic characteristics. We used generalised estimating equations to determine whether pre-pregnancy health conditions and pregnancy complications explained any statistically significantly elevated aRRs.
Results After controlling for socio-demographic characteristics, women with intellectual and developmental disabilities were more likely to have labour inductions (aRR, 1.13; 95% CI 1.06 to 1.20) and caesarean sections (aRR, 1.09; 95% CI 1.03 to 1.16) but not operative vaginal deliveries, compared to the referent group. Pre-pregnancy health conditions explained 12.9% of their elevated aRR for labour induction. Pre-pregnancy health conditions and maternal complications explained 27.8% and 13.3%, respectively, of their elevated aRR for caesarean section.
Conclusions Women with intellectual and developmental disabilities are slightly more likely to have labour inductions and caesarean sections than women without intellectual and developmental disabilities. The elevated occurrence of these interventions is not fully explained by their pre-pregnancy health conditions or pregnancy complications. Non-medical issues should be evaluated for their influence on the timing of labour and delivery in this population. (Author)

20160802-32

Supporting mothers and fathers with learning disabilities. Ewins W (2016), International Journal of Birth and Parent Education vol 3, no 4, Summer suppl 2016, pp 5-6

Reports on a workshop on helping to support parents with learning disabilities which was held at the 2016 International Journal of Birth and Parent Education conference. (9 references) (MB)

20160526-8*

Pregnancy in women with intellectual and developmental disabilities. Brown HK, Lunsky Y, Wilton AS, et al (2016), JOGC [Journal of Obstetrics and Gynaecology Canada] vol 38, no 1, January 2016, pp 9-16

Objective:
Our objectives were to describe the general fertility rate (GFR) and age-specific fertility rates (ASFRs) of women with intellectual and developmental disabilities (IDD) and the social and health characteristics of those with a singleton live birth, and to compare these to women without IDD.
Methods:
In this population-based retrospective cohort study using linked Ontario health and social services administrative data, we identified 18- to 49-year-old women with IDD (N = 21 181) and without IDD (N = 990 776). The GFR and ASFRs (2009) were calculated for both groups and compared using rate ratios (RR) and 95% confidence intervals (CI). Among women with a singleton live birth (N = 423 with, N = 42 439 without IDD), social and health characteristics were compared using Pearson's Chi square tests.
Results:
The GFR in women with IDD (20.3 per 1000) was lower than that in women without IDD (43.4 per 1000) (RR 0.47; 95% CI 0.43 to 0.51). ASFRs in 18- to 24-year-olds were similar in both groups. Among women with a singleton live birth, those with IDD were younger and had higher rates of poverty, epilepsy, obesity, and mental health issues. They also had high rates of medication use during pregnancy.
Conclusion:
In the largest study of fertility in women with IDD to date, we found that ASFRs are similar in young women with and without IDD. Women with IDD with a singleton live birth experience significant social and health disparities during pregnancy. These findings suggest the need to develop services to support the reproductive health of this vulnerable group. (45 references) (Author)

20160525-3*

Maternal and offspring outcomes in women with intellectual and developmental disabilities: a population-based cohort study.
Brown HK, Cobigo V, Lunsky Y, et al (2017), BJOG: An International Journal of Obstetrics and Gynaecology vol 124, no 5, April 2017, pp 757-765

Objective
To compare the risks for adverse maternal and offspring outcomes in women with and without intellectual and developmental disabilities.
Design
Population-based cohort study.
Setting
Ontario, Canada.
Population
Singleton obstetrical deliveries to 18- to 49-year-old women with and without intellectual and developmental disabilities (n = 3932 in the exposed cohort, n = 382 774 in the unexposed cohort; 2002-2011 fiscal years).
Methods
Women with intellectual and developmental disabilities were identified based on diagnoses in health administrative data or receipt of disability income support. The unexposed cohort comprised women without intellectual and developmental disabilities. Modified Poisson regression was used to compute adjusted relative risks (aRR) and 95% confidence intervals (CI) comparing the two cohorts.
Main outcome measures
Primary maternal outcomes were: gestational diabetes, gestational hypertension, pre-eclampsia, eclampsia, and venous thromboembolism. Primary offspring outcomes were: preterm birth, small for gestational age, and large for gestational age.
Results
The exposed cohort, compared with the unexposed cohort, had increased risks for pre-eclampsia (aRR 1.47, 95% CI 1.11-1.93) and venous thromboembolism (aRR 1.60, 95% CI 1.17-2.19). Their offspring had increased risks for preterm birth (aRR 1.63, 95% CI 1.47-1.80) and small for gestational age (aRR 1.35, 95% CI 1.25-1.45).
Conclusions
These findings suggest that there is a need to address modifiable risk factors for adverse outcomes among women with intellectual and developmental disabilities prior to and during pregnancy. Moreover, there is a need to enhance monitoring for maternal and offspring complications in this population. (Author)

20160420-42

Reimagining parenting possibilities: the experiences of people labeled with intellectual and developmental disabilities. Ignagni E, Schormans AF (2016), International Journal of Birth and Parent Education vol 3, no 3, Spring 2016, pp 23-26

This article arises out of ongoing research entitled, 'Re-imagining Parenting Possibilities', that is seeking to learn more about the parenting expectations and experiences of people labeled with intellectual and developmental disability (labeled people) and to help them realize and exercise their right to become parents. It addresses how culturally embedded ideas about 'good' and 'normal' parenting shape how people practice, plan and dream about parenthood, and how such ideas impose standards which marginalize labeled parents. The article also looks at practical issues of access which impede labeled people from obtaining necessary information and support and from utilizing parenting resources. (10 references) (Author)

20160420-27

Social support received by women with intellectual and developmental disabilities during pregnancy and childbirth: an exploratory qualitative study. Potvin LA, Brown HK, Cobigo V (2016), Midwifery vol 37, June 2016, pp 57-64

Objective
This study aims to contribute to the development of a conceptual framework that will inform maternity care improvements for expectant mothers with intellectual and developmental disabilities (IDD) by exploring the structure, functions, and perceived quality of social support received by women with IDD during pregnancy and childbirth.
Design/setting
Using a grounded theory approach, we conducted an exploratory study set in Ontario, Canada in 2015.
Participants
The sample included four adult women with IDD who had given birth in the last five years.
Measurements
Data were collected using semi-structured interviews.
Findings
The structure of social support received by women with IDD consisted of both formal and informal sources, but few or no friendships. Women with IDD reported high levels of informational and instrumental support and low levels of emotional support and social companionship. However, a high level of available support was not always perceived as beneficial. Emergent core categories suggest that social support is perceived as most effective when three conditions are met: 1) support is accessible, 2) support is provided by individuals expressing positive attitudes towards the pregnancy, and 3) autonomy is valued.
Key conclusions and implications for practice
Our study confirms and identifies important gaps in the social support received by expectant mothers with IDD. Women with IDD currently lack accessible informational support, emotional support, and social companionship during pregnancy and childbirth. Additional findings regarding the structure and functions of social support are presented, and a preliminary conceptual framework of effective social support during pregnancy and childbirth, as perceived by women with IDD is also proposed. Findings suggest that increasing support accessibility should be a social and clinical priority; however, maternity care providers should be aware of stigmatizing attitudes and respect the autonomy of pregnant women with IDD as they prepare for motherhood. (Author)

20160219-19

Research with and by people with learning difficulties. Durell S (2016), Nursing Times vol 112, no 6/7, February 2016, pp 15-18

Many people with learning disabilities are frequently excluded from active involvement in research and, as a result, along with researchers, have questioned research processes. These discussions have influenced how research is undertaken by, and with, people who have learning disabilities. Learning disability research is now increasingly framed as inclusive. This article explores the development of inclusive learning disability research by tracing its background and influences, identifying key characteristics and highlighting some of the challenges in its application. It demonstrates how inclusive research can give people with learning disabilities a voice that will help to inform practice. (33 references) (Author)

20160210-13

Midwives' experiences of caring for women with learning disabilities - A qualitative study. Castell E, Kroese BS (2016), Midwifery vol 36, May 2016, pp 35-42

BACKGROUND AND OBJECTIVE:

people with learning disabilities (LD) are increasingly likely to become parents and are entitled to have access to the right support to be able to be suitable parents. However, access to such support is affected by limited resources, attitudes towards people with LD becoming parents, and lack of training regarding caring for parents with learning disabilities for midwives. A learning disability (LD) is defined as a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), reduced skills to cope independently with everyday life, has an impact on most areas of a person's life and the difficulties started in early childhood. Little research has explored health professionals' experiences of their support of people with LD during their journey to become parents. Midwives are often the first professionals pregnant women come into contact with and therefore are key professionals in the support system for parents with LD. The principle objective of the current research is to develop an understanding of midwives' experiences of caring for women with a LD.

DESIGN:

the study explored midwives’ experiences of caring for women with LD using an Interpretative Phenomenological Approach (IPA).

PARTICIPANTS:

nine qualified midwives employed by a single NHS trust participated in the study.

MEASUREMENTS AND FINDINGS:

a semi-structured interview schedule was utilised during one-to-one interviews with the midwives. The interview transcripts were analysed using IPA stages. Four superordinate themes were identified.

KEY CONCLUSIONS:

The midwives reported receiving a lack of LD training and faced significant time constraints, which left them feeling that they could not spend the necessary time with the women to meet their pregnancy needs. The midwives felt unsupported in their attempts to deliver adequate midwifery care, speaking about a lack of accessible support for pregnant women with LD. They were left feeling responsible to fill the gaps in service provision. The midwives were dedicated in delivering adequate care to help give women with LD a positive experience of childbearing. They felt a safeguarding process (child protection) was an inevitable part of women with LD's pregnancy experience yet were aware that the right support at the right time could improve parenting capacity.

IMPLICATIONS FOR PRACTICE:

it is recommended that training on working with and providing services for people with LD is made available to qualified and student midwives as well as accessible resources, professional support and supervision.

(39 references) (Author)

20151111-55*

Pregnancy among U.S. women: Differences by presence, type, and complexity of disability. Horner-Johnson W, Darney BG, Kulkarni-Rajasekhara S, et al (2016), American Journal of Obstetrics & Gynecology (AJOG) vol 214, no 4, April 2016, pp 529-530

Background

Approximately 12% of women of reproductive age have some type of disability. Very little is known about sexual and reproductive health issues among women with disabilities, including what proportion of women with disabilities experience pregnancy. Data on pregnancy are important to inform needs for preconception and pregnancy care for women with disabilities.

Objective

The purpose of this study was to describe the occurrence of pregnancy among women with various types of disability and with differing levels of disability complexity, compared to women without disabilities, in a nationally representative sample.

Study Design

We conducted cross-sectional analyses of 2008-2012 Medical Expenditure Panel Survey data to estimate the proportion of women ages 18-44 with and without disabilities who reported a pregnancy during their 2-year participation on the survey panel. We used multivariable logistic regression to test the association of pregnancy with presence, type, and complexity of disability, controlling for other factors associated with pregnancy.

Results

Similar proportions of women with and without disabilities reported a pregnancy (10.8% vs. 12.3%, with 95% confidence intervals overlapping). Women with the most complex disabilities (those that impact activities such as self-care and work) were less likely to have been pregnant (AOR=0.69, 95%CI=0.52-0.93), but women whose disabilities only affected basic actions (seeing, hearing, movement, cognition) did not differ significantly from women with no disabilities.

Conclusion

Women with a variety of types of disabilities experience pregnancy. Greater attention is needed to the reproductive healthcare needs of this population in order to ensure appropriate contraceptive, preconception, and perinatal care. (Author) (Only the abstract/summary is published in the print journal, even where additional comments and clinical implications have been added)

20151021-16*

Current evidence on antenatal care provision for women with intellectual disabilities: A systematic review. Homeyard C, Montgomery E, Chinn D, et al (2016), Midwifery vol 32, January 2016, pp 45-57

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 birth weight 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. (61 references) (Author)

Full URL: http://www.midwiferyjournal.com/article/S0266-6138(15)00259-4/pdf

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20150714-37*

Meeting the reproductive needs of female adolescents with neurodevelopmental disabilities. Fouquier KF, Camune BD (2015), JOGNN: Journal of Obstetric, Gynecologic and Neonatal Nursing vol 44, no 4, July/August 2015, pp 553-563

The complexity of caring for female adolescents with neurodisabilities often overshadows normal biological changes. These young women may require additional or individualized support as they adapt to normal puberty and sexual maturation. Many choices are available to assist in managing menstrual problems, hygiene issues, and contraception. Special considerations regarding contraceptive methods, sexual education, and improving service accessibility are explored for clinicians. (Author)

20150521-16

Antenatal support for people with learning disabilities. Harrison R, Willis S (2015), British Journal of Midwifery vol 23, no 5, May 2015, pp 344-348

Following the introduction of learning disability nurses in acute and primary care in 2009, several health areas were taken into consideration as a priority for change. Maternity services were considered in order to bring this area into line with the other parts of the UK. This article will examine the provision of services for people with learning disabilities, and identify areas for improvement including educational needs for midwives. Outcomes of an audit and evaluations of local services against national policy and provision will be highlighted, barriers faced by both prospective parents with a learning disability and by professionals will be discussed and recommendations for future practice will be presented. Misleading diagnosis, discrepancies in numbers and training developments will also be addressed.

Despite Government policy identifying that 'reasonable adjustment' must be made when supporting parents with a learning disability, 23 midwives, team managers and health care assistants in midwifery services in Nottinghamshire have highlighted that there is little awareness in the field locally. (22 references) (Author)

20150501-5

Pregnancy, birth and postnatal support for women with intellectual disabilities: the CanDo Doula model. Cox R, Kroese BS, McGarry A (2015), International Journal of Birth and Parent Education vol 2, no 3, Spring 2015, pp 19-22

There continues to be a powerful myth that adults with Intellectual Disabilities cannot learn new skills, therefore will never be able to learn how to be a parent. This is the not the case. Research has demonstrated no strong correlation between IQ and parenting ability (1) and with the correct type of support, people with ID can and do learn new skills and can parent successfully (2). 1.Feldman MA. Parenting education for parents with intellectual disability: a review of the literature. Research in Developmental Disabilities, vol 15, 1994, pp 229-232. 2. Tarleton B et al. Finding the right support: a review of issues and positive practice in supporting parents with learning difficulties and their children. 2006. London: The Baring Foundation. (20 references) (Author, edited)

20150430-33

Engaging mothers and fathers with learning disabilities in antenatal education. Ewins W (2015), International Journal of Birth and Parent Education vol 2, no 3, Spring 2015, pp 7-10

It is now widely recognised that people with learning disabilities typically want the same things in life as everybody else: good friends, good health, their own home, a job and a family. They have the same rights as everybody else to pursue valued social roles. One of the most valued social roles in society is becoming a parent, and throughout the UK and abroad, there are increasing numbers of women with learning disabilities choosing to start a family. (26 references) (Author)

20150206-8

Preventing maternal deaths and overcoming challenges related to disability in pregnant women. Acharya G (2015), Acta Obstetricia et Gynecologica Scandinavica vol 94, no 2, February 2015, pp 123-124

Highlights the need for more consideration of the needs of disabled women in pregnancy and more research so that outcomes can be improved. (8 references) (SB)

20141217-62

Taking it into account: caring for disabled mothers during pregnancy and birth. Payne DA, Guerin B, Roy D, et al (2014), International Journal of Childbirth vol 4, no 4, 2014, pp 228-239

BACKGROUND: Although more disabled women are pursuing motherhood over time, little is known about their needs and experiences in achieving this goal.

METHODS: A 3-phase study was designed with the aim of identifying ways for services to be more responsive for women living with physical or sensory impairment during and after pregnancy. This article draws on the qualitative phases of a 3-part mixed method study, which involved individual and focus group interviews with the women and maternity and child health practitioners.

RESULTS: Sixty-two mothers with either a physical or a sensory impairment and 28 health practitioners participated in the study. Three themes were identified in relation to the current approaches to service provision: that the women were often responsible for educating the practitioners about their impairment, that they often encountered disabling environments, and that it was not uncommon for them to also encounter disabling attitudes from others. Strategies suggested by our participants to improve the provision of maternity services were for women's impairments to be taken into account in the structure and process of service provision and for practitioners to problem solve and think ahead of how to meet the needs of disabled mothers.

CONCLUSION: The need to take the woman's impairment into account was an overarching issue and strategy identified by both women and practitioners. This consideration has relevance not only at the practitioner-women interaction level but also for educational, structural service provision and policy levels. (46 references) (Author)

20140917-4*

Women's voices on health: addressing barriers to accessing primary care. Psarros A (2014), London: Maternity Action 115 pages. May 2014

Maternity Action surveyed 300 women about barriers to accessing primary care and held focus groups with BME women, refugee and asylum seeking women, women living with HIV, LGBT women, and women with learning disabilities. The research was commissioned by the Women's Health and Equality Consortium. (Publisher)

Full URL: https://maternityaction.org.uk/2014/05/womens-voices-on-health-addressing-barriers-to-accessing-primary-care/

20140709-22

Caring for a woman with autism in early labour. Taylor M (2014), British Journal of Midwifery vol 22, no 7, July 2014, pp 514-518

This article is a personal reflection of a student midwife after participating in the care of a women with autism during early labour. The reflection aims to explore and critically discuss the midwifery care needs of a woman with autism, in particular discussing how her care needs may be different from a neurotypical pregnant woman and how this can be facilitated within a hospital setting. (35 reference) (Author)

20140530-34

Identifying parents with learning disabilities. McKenzie K (2014), Nursing Times vol 110, no 22, 28 May 2014, pp 21-23

People with learning disabilities are likely to need additional support when accessing healthcare and, for those who are parents, receiving support at an early stage may help them to keep their child. Health professionals who have contact with expectant mothers early on in their pregnancies are well placed to identify support needs. Providing timely support may be a challenge, particularly if the mother has not been known to learning disability services. This article discusses whether screening tools may offer nurses a quick, easy way of identifying people with learning disabilities. (21 references) (Author)

20140528-59*

Supporting breastfeeding among women on the autistic spectrum. Pelz-Sherman D (2014), Clinical Lactation vol 5, no 2, 2014, pp 62-66

Professionals supporting breastfeeding mothers who are on the autistic spectrum by providing information, guidance, and clinical considerations for lactation in settings that are medical, psychological, or private practice in lactation support, may benefit from this comprehensive overview. The author outlines relevant symptoms and discusses how the practitioner-patient relationship could be impacted by characteristics associated with high-functioning autism and Aspergers, and includes a case study interview with a mother who has Aspergers. Practical guidelines for lactation support are included. (Author)

20140527-18

Professional and social support enhances maternal well-being in women with intellectual disability - A Swedish interview study. Hoglund B, Larsson M (2014), Midwifery Vol 30, no 11, November 2014, pp 1118-1123

OBJECTIVE:
to gain a deeper understanding of the experience of professional and social support during pregnancy and childbirth among women with intellectual disability (ID) in Sweden.
DESIGN/SETTING:
an interview study among 10 women with ID, who had given birth within seven years. Two interviews were performed with each woman and data were analysed with qualitative content analysis.
FINDINGS:
the overarching theme was: Professional and social support enhances maternal well-being in women with intellectual disability. The women described that the midwife and other caregivers contributed to their own insights and supported their mother-to-be process. They were mostly satisfied with the professional care and support during pregnancy and childbirth, based on aspects such as continuity, competence and professional experience of the midwives but also professional approach and working methods. Dissatisfaction and confusion occurred when questions were left unanswered or when the women's special needs were not taken into consideration. Family members, friends and colleagues could also have a supporting role and, together with the health staff, contribute to the well-being of the woman.
CONCLUSIONS:
if professional support and care from midwives and other caregivers is adapted to the special needs of women with ID, it contributes to new insights, enhances well-being and supports the process of becoming a mother. Midwife-led continuity of care together with continuous social support should be offered to pregnant women with ID during pregnancy and childbirth. (Author)

20140522-1*

A mixed methods study to develop and pilot a competency assessment tool to support midwifery care of women with intellectual disabilities. Beake S, Clark LL, Turner T, et al (2014), Nurse Education Today vol 34, no 6, 2014, pp 901-906

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. (Author)

20140103-53

Aiming for equal access to maternity care for all. Homeyard C, Godfrey C, Gaudion A (2014), The Practising Midwife vol 17, no 1, January 2014, pp 13-16

The guidance `Pregnancy and complex social factors' (National Institute for Health and Care Excellence (NICE) 2010) outlines that women with complex social factors are likely to have particular needs and may be faced with barriers to accessing care. This article describes a project to design and develop clear antenatal appointment sheets for various consultations with health professionals in maternity services in an attempt to meet the Royal College of Midwives (RCM) recommendation that: 'Directors of midwifery services should develop resources in partnership with experts and disability advocates in different formats appropriate to need' (RCM 2007: 1). It highlights the rationale, methodology, ethics and findings from the project. The term 'learning disabilities' (LD) is used throughout this article as it is commonly used by services within the UK and internationally to describe people with intellectual disabilities. (15 references) (Author)

20131213-49*

A systematic review of interventions to promote social support and parenting skills in parents with an intellectual disability.
Wilson S, McKenzie K, Quayle E, et al (2014), Child: Care, Health and Development vol 40, no 1, 2014, pp 7-19

The family support needs of parents with an intellectual disability (ID) are relatively unknown. This paper reviewed two types of intervention for parents with ID: those designed to strengthen social relationships and those teaching parenting skills. A literature search was conducted using electronic databases and a limited number of evaluative studies were found. The evidence for interventions aimed at strengthening social relationships was inconclusive; although positive changes were observed, there were limitations in study design which restricted the generalizability of the results. The evidence for parental skills teaching suggested that behavioural based interventions are more effective than less intensive forms such as lesson booklets and the provision of normal services, although these studies also had limitations. There is a need for further large scale controlled studies in this area to provide clearer evidence and to explore additional factors relating to child, parent and family which may impact on outcomes. (Author)

20130806-55*

A mixed methods study to develop and pilot a competency assessment tool to support midwifery care of women with intellectual disabilities. Beake S, Clark LL, Turner T, et al (2013), Nurse Education Today vol 33, no 8, 2013, pp 901-906

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. (Author)

20130805-25

Midwives' knowledge of, attitudes towards and experiences of caring for women with intellectual disability during pregnancy and childbirth: A cross-sectional study in Sweden. Hoglund B, Lindgren P, Larsson M (2013), Midwifery vol 29, no 8, August 2013, pp 950-955

OBJECTIVE: to investigate midwives' knowledge of, attitudes towards and experiences of caring for women with intellectual disability (ID) during pregnancy and childbirth. DESIGN/SETTING: a cross-sectional study among six hundred midwives working at antenatal care and labour wards in Sweden. RESULTS: more than four out of five (81.5%) midwives had experience of caring for women with ID. Almost all midwives (97.1%) reported that caring for women with ID is different from caring for women without ID. Almost one-half (47.3%) had not received any education about pregnancy and delivery of women with ID, and a majority of the midwives (95.4%) requested evidence-based knowledge of women with ID in relation to childbirth. High proportion (69.7%) of the midwives were of the opinion that women with ID cannot satisfactorily manage the mother role, and more than one-third (35.7%) of the midwives considered that women with ID should not be pregnant and give birth at all. Most midwives partly/totally agreed that children of women with ID should grow up with their parents supported by the social authorities, but nearly one-fifth (19.1%) partly/totally agreed that the children should grow up in foster care. CONCLUSIONS: even if the majority of midwives had experience of caring for women with ID, they were uncertain about how to adapt and give advice and they needed more knowledge about these women. Some midwives had negative attitudes towards childbearing among women with ID. Health Service providers should encourage midwives to update their knowledge and provide supportive supervision in midwifery care for women with ID. (27 references) (Author)

20130607-18

Struggling for motherhood with an intellectual disability - A qualitative study of women's experiences in Sweden. Hoglund B, Larsson M (2013), Midwifery vol 29, no 6, June 2013, pp 698-704

OBJECTIVE:
to gain a deeper understanding of the experiences of childbearing in women with intellectual disability (ID).
DESIGN/SETTING:
ten women with ID, who had given birth within seven years, were interviewed twice and data were analysed with content analysis.
FINDINGS:
the overarching theme was: Struggling for motherhood with an ID. The significance of having an intellectual disability became evident when the women encountered mixed reactions from partners and relatives, who sometimes suggested an induced abortion. The women disclosed their diagnosis if they believed it was beneficial for them. Throughout the process the women also felt anxious and distressed about the custody of the child. Women experienced the pregnancy as a physical and psychological transition. It was mostly a happy and responsible life event, and the women were aware of physical signs in their bodies and contact with the unborn child. Parent education was considered important but not adequately adapted to their needs. The women described the delivery as hard and painful work, sometimes difficult to understand and they had different strategies to handle the pain and strain of labour. The child was welcomed with warmth and curiosity by the women, who cared for and breast fed the child even if the hospital environment could be confusing and continued custody not taken for granted.
CONCLUSIONS:
women with ID struggle for motherhood and fear losing custody of the child. Professionals need to identify and support these women, who may not always disclose their diagnosis. Since pregnancy, delivery and the transition into motherhood can be difficult to understand, information and support should be better tailored to their needs. (40 references) (Author)

20130606-54

The postnatal support needs of mothers with an intellectual disability. Wilson S, McKenzie K, Quayle E, et al (2013), Midwifery vol 29, no 6, June 2013, pp 592-598

OBJECTIVE:
there is growing evidence that many parents with intellectual disabilities can parent successfully when given adequate support. This paper aims to explore the postnatal care experiences of mothers with an intellectual disability.
DESIGN:
a qualitative design was used and data were collected using a semi-structured interview format and analysed using Interpretative Phenomenological Analysis.
SETTING:
the study took place in community settings in Scotland.
PARTICIPANTS:
six mothers with intellectual disabilities were interviewed about their experiences.
MEASUREMENTS AND FINDINGS:
two super-ordinate themes are discussed with accompanying subthemes: challenges of providing support and how support was delivered.
KEY CONCLUSIONS:
the mothers valued formal postnatal care, but this was secondary to informal support. How mothers perceived the support impacted on its effectiveness and building effective relationships with professionals presented challenges.
IMPLICATIONS FOR PRACTICE:
the study suggests the structure and quality of the wider support networks of mothers with an intellectual disability are central and should be taken account of by professionals. Providing information and advice in ways that validates the mother's role is also important, particularly as the mother's perception of how help is given can impact on the degree to which mothers engage with professionals. (44 references) (Author)

20130502-12

Normalising birth for women with a disability: The challenges facing practitioners. Walsh-Gallagher D, McConkey R, Sinclair M, et al (2013), Midwifery vol 29, no 4, April 2013, pp 294-299

Previous research on pregnant women with a disability and their experience of maternity care demonstrated that these mothers perceived themselves to be the 'perennial outsiders' with midwives automatically categorising them as 'high risk' because of their disability. They also felt that their ability to make choices, stay in control and have continuity of care was not considered to be part of the mainstream maternity care for them because they did not fit the 'normal' category. Objective: this research was undertaken to explore the perceptions of two multiprofessional teams in Irish hospitals as to how maternity services to these mothers can be improved. Participants: nineteen health-care professionals from midwifery, social work and public health nursing were recruited. Setting: two from two major maternity hospitals, one in the North and one in the South of Ireland. were featured. Design: the method chosen was a qualitative approach, using focus group interviews in which case studies depicting a range and breadth of women's birthing experiences were presented and discussed. Newell and Burnard's (2006) six stage approach to thematic content analysis was used. Findings: the professionals found the disabled women's stories believable, upsetting and challenging. Key conclusions: Staff acknowledged their 'lack of competence, knowledge and skill' regarding disability and felt that, on reflection, their failure to consult and collaborate with disabled women contributed to their failing to provide individualised woman centred care to women with a disability. Implications of practice: A series of recommendations for improved practice was agreed. (27 references) (Author)

20121218-48

Newborns of mothers with intellectual disability have a higher risk of perinatal death and being small for gestational age. Hoglund B, Lindgren P, Larsson M (2012), Acta Obstetricia et Gynecologica Scandinavica vol 91, no 12, 2012, pp 1409-1414

Objective. To study mode of birth, perinatal health and death in children born to mothers with intellectual disability (ID) in Sweden. Design. Population-based register study. Setting. National registers; the National Patient Register linked to the Medical Birth Register. Sample. Children of first-time mothers with ID (n = 326; classified in the International Classification of Diseases 8-10) were identified and compared with 340 624 children of first-time mothers without ID or any other psychiatric diagnosis between 1999 and 2007. Methods. Population-based data were extracted from the National Patient Register and the Medical Birth Register. Main outcome measures. Mode of birth, preterm birth, small for gestational age, Apgar score, stillbirth and perinatal death. Results. Children born to mothers with ID were more often stillborn (1.2 vs. 0.3%) or died perinatally (1.8 vs. 0.4%) than children born to mothers without ID. They had a higher proportion of cesarean section birth (24.5 vs. 17.7%) and preterm birth (12.2 vs. 6.1%), were small for gestational age (8.4 vs. 3.1%) and had lower Apgar scores (<7 points at five minutes; 3.7 vs 1.5%) compared with children born to mothers without ID. Logistic regression adjusted for maternal characteristics confirmed an increased risk of small for gestational age (odds ratio 2.25), stillbirth (odds ratio 4.53) and perinatal death (odds ratio 4.25) in children born to mothers with ID. Conclusions. Unborn and newborn children of mothers with ID should be considered a risk group, and their mothers may need better individual-based care and support. (29 references) (Author)

20121218-41

Mothers with intellectual disability and their babies: a population warranting special consideration. Llewellyn G (2012), Acta Obstetricia et Gynecologica Scandinavica vol 91, no 12, 2012, pp 1353-1356

Biological factors and/or the mothers' social-environmental situation may be responsible for the much higher relative risk for pregnant intellectually disabled women and their newborns reported in articles by Höglund et al. in this issue. This population has increased exposure to key social determinants of health such as poverty and social exclusion. This is compounded by institutional discriminatory beliefs and practices. People with intellectual disability may also struggle to communicate their needs effectively and to be heard and understood by health professionals. Further research is warranted to understand the reasons for two stand-out findings: why rates of stillbirth and perinatal death are significantly higher in this group and whether varying obstetric practices are responsible for the significantly lower use of pain relief during childbirth. Quality health care requires that due attention is given to meeting the specific needs of this vulnerable group of mothers and their newborns. (17 references) (Author)

20120801-35

Inclusion and accessibility. Box L (2011), Disability, Pregnancy and Parenthood International vol 71, Winter 2012/11

Describes a project to develop teaching materials for parents with learning disabilities, as part of the Strengthening Families, Strengthening Communities (SFSC) parent programme. (JSM)

20120731-98

Upholding family rights. Hopkins A (2012), Disability, Pregnancy and Parenthood International no 71, Winter 2010/11

The author describes the work of Family Rights Group (FRG), a charity offering advice to parents, carers and family members in England and Wales whose children are involved with or need social care services. Discusses working with disabled parents to provide them with a professional family advocacy service. (JSM)

20120731-101

Speaking up for families. Evans R (2012), Disability, Pregnancy and Parenthood International no 71, Winter 2010/11

Highlights the services provided by Advocacy Partners Speaking Up, a UK charity working to ensure equal rights and opportunities are offered to those with learning difficulties or mental health disorders. Explains that central to these services is the advocacy service for parents with learning disabilities; originally set up in Cambridgeshire through National Lottery funding, it has now expanded to Peterborough through the Department for Children, Schools and Families Parenting Fund. (2 references)

20120611-31*

A complex case of Down syndrome in mother and fetus: Obstetric and ethical considerations. Stevens JC, Singh T, Dumplacal M, et al (2012), Journal of Obstetrics and Gynaecology vol 32, no 4, July 2012, pp 393-394

Presents the case of a 21-year-old British Bangladeshi primigravida with Down syndrome and severe learning difficulties who, with input from her family, refused termination of pregnancy following a diagnosis of chromosome abnormality in the child she was carrying, after she presented late for booking interview at 19 weeks' gestation. States that difficulties occurred during premature labour at 36 week's gestation because the mother, who did not speak English, was unable to understand the actions or the posture required to carry out a planned instrumental delivery, and caesarean section was therefore performed, resulting in the birth of a baby boy. Discusses the ethical and legal issues involved in cases of this nature. (JSM)

20120503-27

Working together to keep children safe and well when parents have learning difficulties. Selbie J (2012), Community Practitioner vol 85, no 5, May 2012, pp 34-37

A serious case review, where parental learning difficulties were a factor in the serious injury of a child, prompted review and strengthening of the collaborative work between universal children's services an specialist adult learning disability services. Focus groups enabled wider knowledge of the factors that were barriers to good partnership work, and those factors that required strengthening. Consideration of research findings and literature review has informed the development of a local protocol that focuses on the safety and wellbeing of children. (16 references) (Author)

20111003-3197*

The uncelebrated parent: stories of mothers with learning difficulties caught in the child protection net. Booth T, Booth W (2005), British Journal of Learning Difficulties vol 34, no 2, 2005, pp 94-102

This paper presents the stories of three mothers with learning difficulties whose children have been involved in care proceedings. Drawing on the example of the legendary interviewer, Studs Terkel, the authors let the mothers describe their experiences of the child protection system in their own words. From out of their intensely personal accounts comes a political narrative about the role of the state in the policing of marginalized and vulnerable families.

20111003-3196*

Health of mothers with intellectual limitations. Llewellyn G, McConnell D, Mayes R (2003), Australian and New Zealand Journal of Public Health vol 27, no 1, 2003, pp 17-19

OBJECTIVE: To investigate the health status of mothers with intellectual limitations. METHOD: The health status of 50 mothers with intellectual limitations in metropolitan Sydney was assessed during the baseline assessment phase of a randomised controlled trial of a parent education program. RESULTS: Self-reported maternal health was significantly worse than women's health in the Australian population. Controlling for socio-economic status, mothers' health remained significantly worse on four of the eight subscales. CONCLUSIONS: The findings suggest that mothers with intellectual limitations are particularly at risk for poor health status. An urgent need exists for policy and service initiatives to address the health status of this group of vulnerable mothers. (Author)

20110216-8*

Delay to ruling over sterilisation. Taylor J (2011), Independent 15 February 2011

Reports that the mother of a 21-year-old woman with severe learning difficulties who is about to give birth to her second child by caesarean section has asked the Court of Protection to take measures to prevent her from having any more children, because she is unable to care for them herself. States that Mr Justice Hedley has postponed a decision on whether or not the woman should have sterilisation by tubal ligation or a less invasive procedure such as a contraceptive implant until expert evidence can be obtained. Explains that the Court of Protection exists to deal with the financial, medical and personal affairs of those who are unable to make such decisions themselves; hearings are usually held in private but this case is being held in open court because of the level of public interest. (JSM)

Full URL: http://www.independent.co.uk/news/uk/home-news/delay-to-ruling-over-sterilisation-2215867.html

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20101124-7*

Pregnancy, Birth and Early Parenthood - a guide for physically disabled parents'. Disability, Pregnancy and Parenthood international (2010), London: DPPi 2010

Offers practical information and guidance for physically disabled parents and the health and social care professionals who support them. Covers all stages of having a baby, including preconception care and planning, antenatal care and birth choices, and adjusting to life as a parent. (JSM)

20101124-5*

The challenges of disability and pregnancy. Rushby Smith T (2010), The Guardian 23 November 2010

Presents the author's experience, and the experiences of others who have entered into parenthood with a disability. Describes the challenges they have faced, including reactions from GPs, obtaining financial support, and the fact that in some areas disabled parents are regarded as a child protection issue by social services. Introduces a new guide (1) from Disability, Pregnancy and Parenthood international (DPPi), produced for disabled parents and containing information on pregnancy, professional help, antenatal care and practical parenting, and the range of specialised equipment available on the market. 1. DPPi (2010). Pregnancy, birth and early parenthood - a guide for physically disabled parents. London: DPPi. (JSM)

Full URL: http://www.guardian.co.uk/society/2010/nov/23/challenges-disability-pregnancy

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20101108-88#

Reaching all parents: Working with parents who have learning disabilities. Ewins W (2010), New Digest no 52, October 2010, p 10

Wendy Ewins, a student NCT antenatal teacher, reports on a project to meet the needs of parents with learning disabilities. (9 references) (Author)

20100217-135*

Do parents with learning disabilities have adequate parenting skills to safeguard their children?. Macdonald L (2009), Journal of Neonatal Nursing vol 15, no 6, December 2009, pp 212-

The aim was to look at parents with learning disabilities and explore the assessment process which determines whether these parents are able to provide adequate parenting skills to enable their children to achieve optimal outcomes in a safe environment. It explores the support networks available to parents and examines the role of the neonatal nurse in this process. Throughout reference is made to child protection issues and will always focus on the effect on the child. The findings suggest that interagency communication needs to be improved and we must remember to focus on the best outcome for the child. (Author)

20100114-85

Women with disabilities: the midwife's role and responsibilities. Lawler D (2010), Practising Midwife vol 13, no 1, January 2010, pp 20-23

Argues that maternity services are not meeting the needs of pregnant women with disabilities. Describes the specific issues that need to be addressed and discusses the role and responsibilities of the midwife in providing woman-centred care during pregnancy, childbirth and postnatally. (42 references) (JSM)

20091110-10*

Pregnant woman flees social workers. Reid M (2009), Times 10 November 2009

Reports that Kerry Robertson and her fiance, Mark McDougall have fled their home in Scotland in order to escape plans by Fife Council to take their baby away when it is born in January. Explains that 17-year-old Miss. Robertson has learning difficulties and the couple have already had their plans to marry quashed by social workers who questioned her ability to make an informed decision about getting married. States that Fife Council have said no decision will be made until the baby is born. (JSM)

20091022-51

Parents with learning disabilities: perceived incidence and needs. Barkby H, Talbot A, Lee A, et al (2009), Community Practitioner vol 82, no 11, November 2009, pp 34-37

Recent literature and government guidance has highlighted the rights of parents with learning disabilities and role of services in meeting their needs. In the present study, three focus groups were conducted involving 35 members of community health visiting teams in order to identify estimated incidence and needs of parents with learning disabilities and the needs of services in supporting them. The health visiting teams identified clinically significant numbers of parents with learning disabilities and - through qualitative focus group discussion - suggested a significant need for intervention and support for these parents, greater resources and knowledge within health visiting services, and improved interagency co-ordination and communication. (17 references) (Author)

20091021-42*

Couple fight council to keep baby. BBC News (2009), BBC News 19 October 2009

Highlights the case of a 17-year-old pregnant woman who has been told the council may take her baby away from her because she has learning difficulties. Reports that Kerry Robertson has also been prevented from marrying her fiance, Mark Dougallson, because social workers have said she does not have the capacity to consent to the wedding, and that she is now involved in a legal dispute to determine if she has the mental capability to consent to marriage, and the couple are also fighting to keep their baby and for the right to be a family. (JSM)

20090904-71*

Indian woman fights for 'rape' baby. Ray T (2009), BBC News 4 September 2009

Reports the case of a 19-year-old Indian girl with the mental age of eight, who is pregnant after being raped while in a government-run care home. States that the case is hitting the headlines in India where the local court ruled she should have an abortion after hearing from the state authorities that she would not survive the trauma of childbirth or be able to take care of the baby, only to be over-ruled by the Supreme Court who were approached by the girl's lawyers and several disability rights groups, meaning that the girl will be able to keep her baby when it is born in December. (JSM)

20090219-26

The right support: helping parents with learning disabilities to parent well. Tarleton B (2009), New Digest no 45, January 2009, p 8

Beth Tarleton, researcher at Bristol University, discusses the needs of parents with learning disabilities and the resources available to professionals working with them. (3 references) (Author)

20080604-45

Marriage and sexual intercourse: autonomy and capacity to consent. Symon A (2008), British Journal of Midwifery vol 16, no 6, June 2008, p 407

Comments on the case of a 26-year old Bangladeshi man with significant cognitive impairment, who was married by telephone to a young Bangladeshi woman. Discusses the legal issues involved in capacity to consent to marry and to engage in sexual relations and discusses the midwife's role in caring for a pregnancy that may potentially result from such a union. (3 references) (MB)

20080425-17*

Pregnancy and disability: RCN guidance for midwives and nurses. Rotheram J (2007), London: Royal College of Nursing March 2007. 29 pages

Provides guidance for midwives and nurses involved in the care of disabled women during pregnancy, labour and the postnatal period. (JSM)

20080425-11

Guidance for midwives and nurses. Rotheram J (2007), Disability, Pregnancy and Parenthood International no 58, Summer 2007

Considers some of the issues around pregnancy and disability and questions whether the lack of literature on the topic suggests that it is generally assumed that disabled women do not want to become parents or are not capable of parenting. Highlights the need for nurses, midwives and carers to be equipped to deliver evidence-based, woman-centred care in order to meet the needs of the individual, and therefore help make pregnancy and childbirth a positive experience. Explains how a new publication (1) can assist them in doing this. 1. Rotheram J (2007). Pregnancy and disability: RCN guidance for midwives and nurses. London: Royal College of Nursing. (JSM)

20080423-110

Midwives gain valuable insights. Killick Z (2006), Disability, Pregnancy and Parenthood International vol 53-54, Spring/Summer 2006

Describes aspects of midwifery education at the Anglia Ruskin University in Chelmsford which look at caring for parents with disabilities or special needs. (JSM)

20080227-45

Pregnancy and active Huntington disease: a rare combination. Hoskins KE, Tita ATN, Biggio JR, et al (2008), Journal of Perinatology vol 28, no 2, February 2008, pp 156-157

We describe the complicated course of a rare pregnant woman with symptomatic Huntington disease (HD) and discuss multidisciplinary care issues that may be encountered. A 31-year-old gravida 2, para 1 with advanced HD was admitted at 30 weeks gestation for preterm labor. Her course was complicated by progressive cognitive and physical impairment, dysphagia, malnutrition, diabetes insipidus, aspiration pneumonia, chorioamnionitis, preterm delivery and pyelonephritis. Pregnant women with symptomatic HD may present multiple challenges requiring extensive multidisciplinary input. (6 references) (Author)

20080213-83

Reflections on the PDN and Parenting with a Disability. Forster S (2007), Parenting with a Disability Bulletin vol 10, no 4, Winter 2007-2008, pp 12-15

Interview in which Susan Forster, one of the founding members of the Parenting with a Disability Network (PDN), answers questions on how the organisation came into being, and the progress made since the early days. (JSM)

20071026-52

Midwives' skills, knowledge and attitudes: how they can affect maternity services. McKay-Moffat S (2007), In: Disability in pregnancy and childbirth. Edinburgh: Churchill Livingstone 2007. pp 115-137

Gives an overview of midwives' attitudes and experiences of working with disabled women. (24 references) (CB)

20071026-51

Women with intellectual disabilities. Moss L (2007), In: Disability in pregnancy and childbirth. Edinburgh: Churchill Livingstone 2007. pp 95-113

Discusses the gradual changes in attitude towards people with learning disabilities becoming parents. It highlights the importance of developing maternal health services from having a 'one size fits all' approach to a more supportive and accepting approach. It also explores the process of educating women about intercourse, pregnancy, childbirth and the postnatal period. (40 references) (CB)

20071026-48

Women's health and disability. McKay-Moffat S, Lee P (2007), In: Disability in pregnancy and childbirth. Edinburgh: Churchill Livingstone 2007. pp 19-47

Gives an overview of issues surrounding disabled women and maternal health care including pregnancy, contraception, abortion and successfully having sex. (56 references) (CB)

20071010-7

Pre-registration midwifery training: including learning disabilities. Gibson T (2007), British Journal of Midwifery vol 15, no 10, October 2007, pp 626-630

Government policy and legislation now oblige mainstream services, including midwifery, to consider the needs of people with learning disabilities in planning and care delivery. However evidence indicates that professionals are not always afforded the training required to enable them to provide effective care for this group. This article describes the development and initial delivery of two half study days on the BSc in Midwifery Studies. The aims of the half study days are to equip student midwives with the basic knowledge and skills to facilitate their care delivery to people with learning disabilities in general but in particular to parents with learning disabilities. The content of the half study days are set out along with a consideration of student evaluations and strategies to improve future delivery. It is hoped that this will stimulate debate regarding the best way forward in the provision of learning disabilities material within undergraduate midwifery education. (27 references) (Author)

20070914-23*

Disability in pregnancy and childbirth. McKay-Moffat S (2007), Edinburgh: Churchill Livingstone 2007. 219 pages

Although an increasing number of women with disabilities are having children, the needs of this minority group are not always being effectively met. Disability in Pregnancy and Childbirth provides essential practical information to healthcare professionals working with this group. (Publisher). This timely and informative book fills the void where so few books are available that discuss how women living with a disability feel about using maternity services in the UK. Concrete examples are given which highlight good practice in meeting the needs of women with disabilities alongside a discussion of the failure of some health professionals to provide an effective maternity service for such women. While the more common disabilities are discussed, such as visual or hearing impairments and intellectual disabilities, other disabilities are included which may not be so familiar but which midwives may encounter when caring for a woman or her partner. Suggestions for improving care at a service provision and individual level are discussed throughout using case scenarios and photographs of available equipment. Useful addresses and websites are also included for both midwives and women; these might also form a useful means for networking with other women or organisations that may be able to help. Where some disabilities are rare, and midwives are unlikely to have experience of these on a regular basis, being able to access organisations that have specific expertise can be of considerable help. The authors call on midwives to review their skills, knowledge and attitudes about women with disabilities, as well as the need to raise awareness for better midwifery and medical education about the whole range of disabilities and their relationship to care needs. In line with recent government proposals, the authors also call for more user involvement in planning maternity services and encourage us to reflect on how we can improve care at an organisational level and also in our everyday encounters with what may be an increasing number of clients with unique needs. These may challenge us to meet our legal and statutory responsibility to offer high standards of care to all women who use our services.
Reviewed by Bernadette Gregory, senior lecturer in midwifery, De Montfort University, Leicester.

20070912-5

Working with parents who have a learning disability. Thurtle V, Nichols C, Gatt B (2007), Community Practitioner vol 80, no 9, September 2007, pp 10, 12

New guidance looks at ways parents with a learning disability can be supported. (8 references) (Author)

20070122-18

A challenging clinical experience: when both child and family care needs are complex. Wright JA (2006), Pediatric Nursing vol 32, no 6, November-December 2006, pp 583-586

A paediatric nurse describes the challenging but rewarding experience of helping parents with developmental disabilities to be able to care for their newborn daughter with special medical needs. (CR)

20061219-20

Using the Edinburgh Postnatal Depression Scale with learning disabled mothers. Gaskin K, James H (2006), Community Practitioner vol 79, no 12, December 2006, pp 392-396

Accurate identification of postnatal depression in mothers with a learning disability is essential if they are to be offered appropriate treatment and support. However, health visitors have raised concerns about the usefulness of the Edinburgh Postnatal Depression Scale (EPDS) with this group of women. In this small-scale study, mothers with a learning disability were asked to complete an EPDS and take part in a structured interview, which was designed to be more appropriate to their level of intellectual ability. The number of symptoms they described was compared with those observed by a significant other person in their lives. The simplified interview, using a visual scale to depict severity of symptoms, seemed to collect more accurate information than the EPDS, giving a higher correlation with observed symptoms. When compared with this interview, the EPDS scores appeared to overestimate symptoms or identify symptoms not observable by those close to the participants. Validation of this scale with a larger group of participants could be a useful development. (19 references) (Author)

20060822-68

Learning disability and parenting. Williams LKM (2006), MIDIRS Midwifery Digest vol 16, no 3, September 2006, pp 315-317

In this article, the author explores the attitudes of society to people with learning disabilities having relationships and children, starting by looking at how things have been in the past and how perceptions have changed - or not. She describes how this vulnerable group can be helped to be very satisfactory parents and the role of the midwife in this. (29 references) (VDD)

20060322-1*

Access to maternity services research report. Dartnall L, Ganguly N, Batterham J (2005), London: Department of Health 16 November 2005. 77 pages

This report gives the results of a qualitative research into access to maternity services. The overall aim of the research was to identify how the Department of Health could encourage 'hard to reach' groups to take advantage of maternity services by providing suggestions for improving access to, and quality of, maternity service provision. (Publisher)

20060314-17

Family nursing and parents who have a learning disability. Tagg L, Kenny G (2006), Paediatric Nursing vol 18, no 2, March 2006, pp 14-18

Parents who have learning difficulties pose profound questions to the philosophy and practice of family nursing. Failure to recognise how care delivery needs to change in the context of parents with a learning disability can perpetuate discrimination and inequalities for adults and their children. In this paper we explore the neglected topic of adults who have learning disabilities and the problems they face when they become parents. We examine the issue of the rights of adults with learning disabilities and illustrate that when these rights are not upheld they increase the vulnerability of the adults and their children. The implications of these issues are highlighted in the context of children's nursing practice. (40 references) (Author)

20050602-54

Social exclusion: parents with learning disabilities. Pollock L (2005), RCM Midwives Journal vol 8, no 6, June 2005, p 249

Parents with learning disabilities are often the victims of discrimination, but many of the problems they face are caused by a lack of accessible information. Laurence Pollock explains the steps being taken by the charity CHANGE to address this. (Author)

20050110-71*

Supporting disabled adults as parents. Olsen R, Tyers H (2004), York: Joseph Rowntree Foundation November 2004. 4 pages

The National Family and Parenting Institute undertook research into improving supportive practice for disabled parents. The study drew on discussions with parents and visits to four local authorities which have already begun to develop work in this area. (Author)

20040909-11

Disability and reproduction. Earle S, Church S (2004), Practising Midwife vol 7, no 8, September 2004, pp 32-34

Sarah Earle and Sarah Church look at the challenges posed by disabled people who want to bear and raise children. Includes a discussion of disabled people's attitudes towards prenatal screening for abnormalities. (28 references) (Author, edited)

20040820-32

Access all areas. Cohen D, Hebert K (2004), BMJ Careers 21 August 2004, pp 78-79

In their first feature looking at the impact of the extended Disability Discrimination Act, which will be implemented this October, Deborah Cohen and Karen Hebert focus on what services providers should be doing to remove access barriers for their patients and staff. (3 references) (Author)

20040614-21

Addressing barriers: disabled rights and the implications for nursing of the social construct of disability. Richardson M (1997), Journal of Advanced Nursing vol 25, no 6, June 1997, pp 1269-1275

Drawing upon the writings of disabled people, this paper explores some of the issues which nurses working with disabled people are trying to address, in particular the barriers model of disability. Traditionally disability has been regarded as a personal tragedy afflicting the individual, hence the response to disability has been via the charity, health and welfare systems. Disabled people over the past two decades have substantially challenged this view of disability and the responses it prompts, arguing that disability is created by social barriers and barriers in the built environment. This requires a different response. Nurses working with disabled people, such as learning disability nurses, have struggled to develop more appropriate responses to disability, for example by developing working alliances with people with learning difficulties in order to both promote health and address disabling barriers. The issues these nurses face and some of the lessons disabled people have taught them are relevant to the nursing profession's wider struggle to shed its medical and dependency image. (47 references) (Author)

20040405-8*

Guide to the care of women with disabilities. Welner S, Haseltine F, eds (2004), Philadelphia: Lippincott Williams and Wilkins 2004. 396 pages

Provides a guide to the care of women with disabilities for doctors, nurses and other health care professionals. It addresses issues of routine care for disabled women and includes chapters on contraception choices, neurological conditions in pregnancy, preparation for pregnancy and the postnatal period, obstetric anaesthesia, and infertility. (SB)

20040202-56

Licence to love. Jackson L (2004), The Guardian 14 January 2004, pp 16-17

After being judged unfit to be parents, a couple with learning difficulties are finally being allowed to bring up their son. (Author)

20030630-22

Tailor-made maternity services. Brown J (2003), Disability, Pregnancy and Parenthood International no 42, Spring 2003, pp 8-9

Report of a multi-professional approach to improving accessibility at Queens Medical Centre, Nottingham, England. (MS)

20020827-41

A low-IQ couple wanting children. Quilliam S, Dalrymple J, Whitmore J (2001), Practitioner vol 245, no 1622, May 2001, pp 359-374

Advice given to a practitioner caring for a woman with learning difficulties who wishes to become pregnant, against the wishes of her parents.

20020327-12

Support for pregnant women. Martin H (2002), Nursing Times vol 98, no 10, 7 March 2002, pp 38-39

Hemmie Martin reports on the special needs of women with learning disabilities during pregnancy and childbirth and the maternity care that is provided in the United Kingdom. (Author)

20010718-12

The introduction of a special needs advisor. Brown B (2001), British Journal of Midwifery vol 9, no 6, June 2001, pp 348-351

The change in the health service over recent years has also resulted in changes to the maternity services. In 2001, government policy making is increasingly being influenced by the views of consumers. However, despite these changes, an area which could still benefit from reform is that of women with special needs. The Disability Discrimination Act 1995 (Department of Education and Employment, 1995) makes it unlawful to offer a lower standard of service to women with disabilities. Therefore it is in the interest of the maternity services to look at ways to provide equal care to these women and their families. This article covers how a special needs advisor could be introduced into a maternity service, follows through the problems this change may cause and suggests ways to overcome these problems. (26 references) (Author)

20010531-49

When parents have learning difficulties. Richardson N (2001), Nursing Times vol 97, no 17, 26 April 2001, pp 40-41

Given positive support, people with learning difficulties can make capable parents. (12 references) (Author)

20000713-07*

The parenting book for persons with a disability: from planning your family to raising adolescents. Centre for Independent Living in Toronto (1999), Toronto, Canada: Centre for Independent Living in Toronto 1999. 140 pages

Created in Canada by parents and persons contemplating parenthood where one or both parents have a disability. The book offers practical advice and information to individuals and families as they anticipate the steps and stages in their child's life, from the decision to have a baby (or to adopt), to the baby's birth, infancy, the toddler years, and beyond. Developed by an advisory committee which combined consumer expertise with practical and professional knowledge, the book is also intended to be a source of information for health care professionals an d other service providers. (Author, edited)

20000215-38

The wall and the ladder. Marks B, Cross G (2000), Practising Midwife vol 3, no 2, February 2000, pp 26-27

The 'Right from the Start' project was set up by the Maternity Alliance in 1996 to look at issues relating to maternity care for women with learning disabilities. As part of its aims is to involve women with learning disabilities in discussing maternity services the Canterbury Partnership Group, a focus group of five women, was set up. This article describes a particular exercise, called 'the wall and the ladder', a technique used as a brainstorming exercise. (KL)

20000102-27*

Maternity services for women with learning difficulties: a report of a partnership of midwives, community nurses and parents. Maternity Alliance (1999), London: Maternity Alliance 1999. 42 pages

In 1996 the Maternity Alliance launched a three-year project investigating ways to improve the maternity services for people with learning difficulties. This report describes how the Canterbury Partnership Group developed ways of improving the involvement of women with learning difficulties through the use of exercise, discussion and reflection, highlighting areas for adaptation and change within the maternity services. (KL)
