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Pregnancy and Postnatal Outcomes for Women with Intellectual Disability and Their Infants: A Systematic Review

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Abstract

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 articles 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.

Keywords: Intellectual disability; Learning disability; Systematic review; Pregnancy; Infant outcomes

Pregnancy and Postnatal Outcomes for Women with Intellectual Disability and Their Infants: A Systematic Review

Introduction

The pregnancy and postnatal period of up to 12 months following birth (hereafter referred to as the perinatal period) is a vulnerable time for women and their infants due to potential physical, mental, and social complications (O'Hara & Wisner, 2014; Yazdkhasti et al., 2014). Potential physical problems in this period include pregnancy, labour, and –delivery complications (e.g. pre-eclampsia, preterm birth), whilst possible mental health complications include the onset or exacerbation of mental illness such as mood disorders or postpartum psychosis. Health in the perinatal period can influence infant development and impacts longer-term outcomes in both the child and the mother (Neiger, 2017; Stein et al., 2014).

Intellectual disability, present in approximately 1% of the population, is a lifelong condition characterised by impairments in global intellectual ability and adaptive functioning that arise during the developmental period (World Health Organization, 2019; Maulik et al., 2011). Causes of intellectual disability include certain genetic syndromes, which can occur spontaneously or may be inherited, in-utero insults, and adverse birth events that lead to complications such as fetal hypoxia. Intellectual disability may also arise following childhood severe head trauma, central nervous system infection, or poisoning. In many cases, however, the cause of intellectual disability is not known. People with intellectual disability have worse physical and mental health than those without intellectual disability across the lifespan (Havercamp et al., 2015; Mazza et al., 2020), and experience health inequities arising, in part, from barriers to accessing timely and effective healthcare (White et al, 2023; Gréaux et a, 2023).

Well into the twentieth century, prevailing social attitudes were such that people with intellectual disability were largely viewed as being incapable of living independently or having families, and involuntary sterilisation and termination of pregnancy were

sometimes used to prevent women with intellectual disability from having children (Tilley et al., 2012). With increased recognition of the rights of people with intellectual disability, the closure of long-stay institutions, and adoption of the 'normalisation' agenda (that is, supporting people with intellectual disability to have the same opportunities and conditions of life as other citizens (Wolfensberger et al., 1972), the potential for women with intellectual disability to develop intimate relationships and raise families increased (Harrison et al, 2021; Johnson et al., 2001). Nevertheless, people with intellectual disability remain at risk of stigma, discrimination, and social isolation and exclusion (Scior et al, 2016; Louw et al, 2020).

A small number of studies have explored how fertility rates of women with intellectual disability compare with those of the general population. One Canadian study, undertaken using administrative records, reported a fertility rate of 20.3 per 1,000 in women with intellectual and developmental disabilities which was significantly lower than the rate of 43.4 per 1,000 recorded in those without intellectual and developmental disabilities (Brown et al., 2016). In contrast, a US longitudinal study showed no significant difference in rates of pregnancy during study follow-up between women with broadly defined 'cognitive disabilities' and those with no disability (Horner-Johnson et al., 2016). An English national survey of almost 3,000 people with intellectual disability in 2003/4 reported that 9% of women with intellectual disability had children, although only around half of these were looking after their child (NHS Digital, 2005). More recently, Baines et al. (2018) used data from a nationally representative English sample of young adults and found that women with mild-moderate intellectual disability were more likely to report having been pregnant and more likely to report being mothers by the age of 20 years than their counterparts without intellectual disability. The mixed findings of studies investigating fertility rates in women with intellectual disability may be explained by differences in study methodology, including in sample population (particularly whether intellectual disability was included as a standalone group or amalgamated with a wider range of disabilities), the country and time period over which data are reported, and the sampling frame.

There is limited evidence concerning maternity services available to women with intellectual disability and on their experiences during pregnancy and the postnatal period. Existing systematic and scoping reviews on pregnancy experiences have generally highlighted the challenges that women with intellectual disability face in accessing antenatal care including communication barriers, lack of suitably adapted care, and negative attitudes from healthcare staff (Homeyard et al., 2016; Ransohoff et al., 2022; Greenwood & Wilkinson, 2013). Qualitative studies of women with intellectual disability have focused on pregnancy and postnatal experiences and the support they have received - findings highlight that access to doulas, midwives, or having a support network are beneficial for the overall experience of women with intellectual disability (Cox et al., 2015; Höglund & Larsson, 2014; Malouf et al., 2017; McGarry et al., 2016). Thus, this limited focus marks an important knowledge gap and impedes attempts to improve practice.

The aim of this systematic review is to explore the pregnancy and postnatal outcomes of women with intellectual disability and their infants to inform future research and the maternity support provided to women with intellectual disability.

Methods

Search strategy

The review protocol was registered with the PROSPERO database of systematic reviews (http://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42023450680) and was conducted according to PRISMA guidelines (Page et al., 2021).

Three electronic databases (MEDLINE, PsycINFO, EMBASE) were searched from inception to 3rd August 2023. Search terms included three concepts: intellectual disability, pregnancy, infant outcomes, and their synonyms (Supplementary Table 1). After removing duplicates, all citations were screened by title and abstract to exclude clearly irrelevant articles. The full text of remaining articles was obtained and assessed for eligibility. Title, abstract and full-text screening was conducted independently by

two researchers, with any discrepancy resolved through discussion with a senior member of the research team. Backwards and forward citation tracking was undertaken on the final list of eligible studies to ensure no relevant studies had been missed.

Eligibility criteria

Studies were eligible for inclusion if they included women with intellectual disability, defined using an internationally recognised classification system (e.g. the Diagnostic and Statistical Manual of Mental Disorders or the International Classification of Diseases). Studies including a broader group of participants, such as those with intellectual and developmental disabilities (including autism and other neurodevelopmental disorders) were included only if the results for people with intellectual disability were reported separately. Observational studies published in a peer-reviewed journal in English (or where an English translation was available) were included. Studies must have reported pregnancy, labour, or postnatal outcomes in women, or neonatal / infant outcomes in the first 12 months of life. Outcomes of interest were not pre-specified and could be of any type, such as maternal obstetric variables, markers of health, and infant developmental outcomes. Abstracts, conference papers, and academic theses were excluded.

Data extraction

Data from included studies were extracted using a data collection form designed for this study. Study characteristics included year of publication, country, and study design. Data related to women with intellectual disability and any comparison group reported were extracted; participant characteristics included socio-demographic variables (e.g. age, socioeconomic status, living situation, co-occurring medical conditions, ethnicity). Measured outcomes, their rates in the intellectual disability and comparator group, and any statistical test were noted.

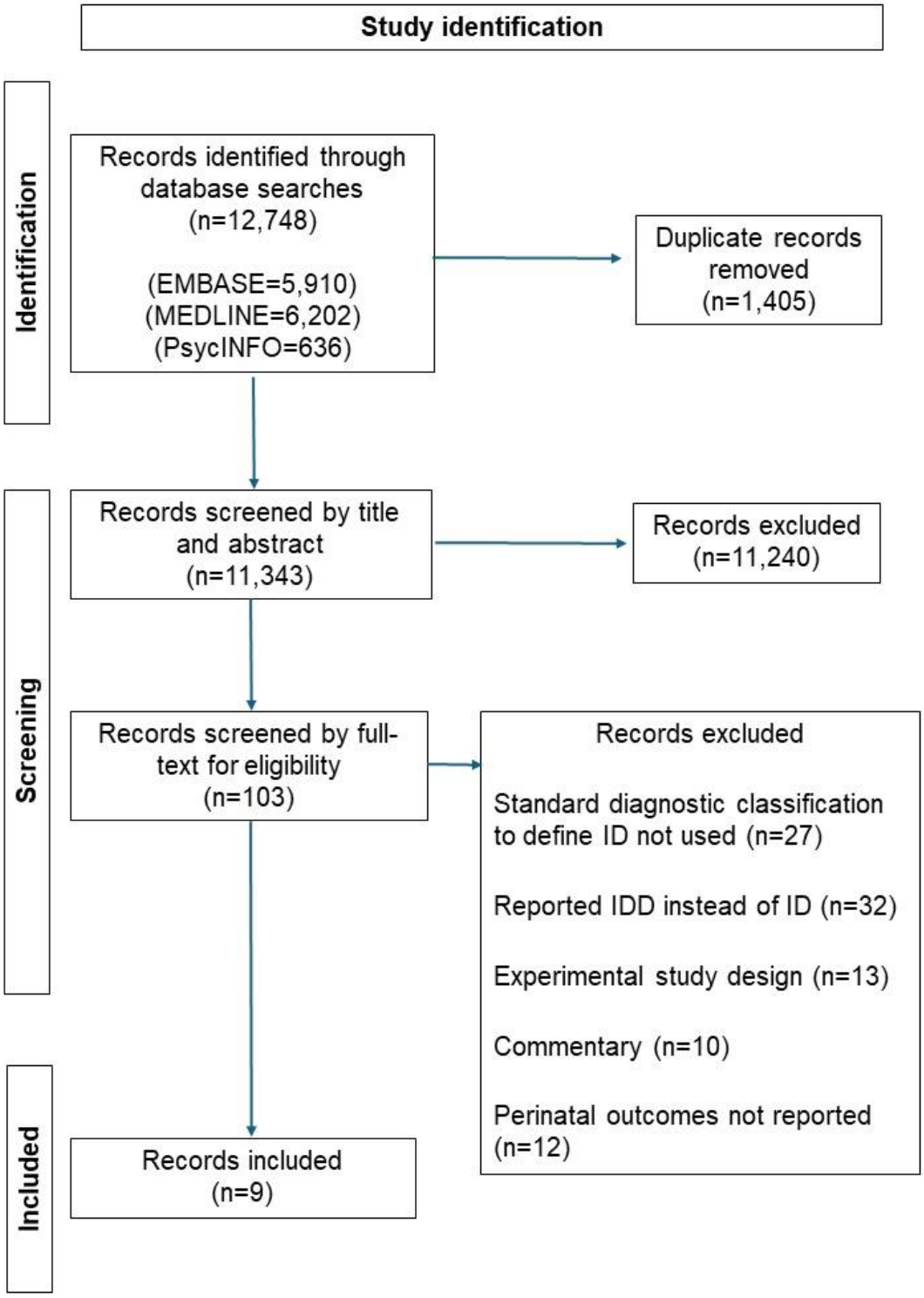

Figure 1 PRISMA flow diagram.

ID, intellectual disability; IDD, intellectual and developmental disability

Data synthesis

Findings were synthesised narratively which included 1) study characteristics, 2) a summary of participant socio-demographic and baseline health data, and 3) pregnancy and post-natal variables broadly categorised into maternal obstetric outcomes (e.g. gestational diabetes, caesarean delivery) and outcomes related to the infant (e.g. birthweight, perinatal death).

Quality appraisal

The National Institutes of Health (NIH) 'Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies' was used to assess the risk of bias of the included studies (National Heart, Lung, and Blood Institute, 2019). This instrument includes 14 questions that are used to appraise the internal validity, selection bias, information bias, measurement bias within a study. Two researchers conducted the appraisal independently and agreed ratings; included studies were given an overall quality rating of good, fair, or poor.

Results

The initial literature search yielded 12,754 records, of which 11,349 remained after duplicates were removed. One hundred and three papers underwent full-text review. After applying inclusion and exclusion criteria, 9 articles reporting findings from 8 cohorts comprised the sample (Figure 1); Rubenstein et al. (2020) reported maternal outcomes and Rubenstein et al. (2021) reported neonatal outcomes from the same cohort.

Study characteristics

Table 1 provides an overview of the characteristics of included studies. Included studies utilised routinely collected health data from birth records, hospital discharge

summaries, death registration records, or national records. Hindmarsh et al. (2015) used data collected as part of the Millenium Cohort Study (MCS), a study in which participants recruited from across the United Kingdom are followed-up using periodic routine surveys. Maternal intellectual disability was defined in most studies according to the World Health Organization International Classification of Diseases (ICD), with eligible mothers/infants identified through insurance claim data (Rubenstein et al, 2020; Rubenstein et al, 2021), interrogation of health records (Fairthorne et al, 2020; Gleason et al, 2023; Goldacre et al, 2015; Hindmarsh et al, 2015; Hoglund 2012a; Hoglund 2012b; Mueller et al, 2019), often making use of data linkage between health registers. One study recruited participants directly and ascertained those with intellectual disability through self-report (Hindmarsh et al, 2015).

All included articles comprised samples from high income countries - the United States (Gleason et al., 2023; Mueller et al., 2019; Rubenstein et al., 2021; Rubenstein et al., 2020), United Kingdom (Goldacre et al., 2015; Hindmarsh et al., 2015), Sweden (Höglund et al., 2012a; Höglund et al., 2012b), and Australia (Fairthorne et al., 2020). The oldest dataset included data from 1970 to 1989 (Goldacre et al., 2015), while the most recent reported data from 2007 to 2016 (Rubenstein et al., 2021; Rubenstein et al., 2020). All included studies had comparison groups of women without intellectual disability. Seven studies were reported as 'good' quality using the NIH quality appraisal tool and two studies were of 'fair' overall quality (Supplementary Table 2).

Across the papers, women with intellectual disability were consistently found to be younger in age (Gleason et al., 2023; Goldacre et al., 2015; Hindmarsh et al., 2015; Mueller et al., 2019; Höglund et al., 2012a; Höglund et al., 2012b), of lower socioeconomic status (Fairthorne et al., 2020; Goldacre et al., 2015), and were more likely to be unmarried (Goldacre et al., 2015; Hindmarsh et al., 2015; Mueller et al., 2019) compared with those without intellectual disability. No consistent findings were reported regarding parity.

In terms of health indicators, women with intellectual disability when compared to those without had higher rates of smoking (Fairthorne et al., 2020; Gleason et al., 2023;

Goldacre et al., 2015; Hindmarsh et al., 2015; Mueller et al., 2019; Rubenstein et al., 2020; Höglund et al., 2012a) and one study reported higher rates of all pre-pregnancy medical conditions that were measured (i.e. asthma, depression, anxiety, HIV, hypertension, pre-gestational diabetes, and renal, heart or thyroid disease) (Gleason et al., 2023).

No significant differences in BMI or weight between women with and without intellectual disability were found with the exception of one study where women with intellectual disability were more likely to be underweight or obese (Rubenstein et al., 2020).

Data on access to health insurance programmes or other government healthcare programmes in women with and without intellectual disability were reported by studies originating in the USA. In terms of access to perinatal care, women with intellectual disability were more likely part of The Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) (Mueller et al., 2019; Rubenstein et al., 2020), a programme to provide healthcare and nutrition for low-income women and their children under five years of age (Food and Nutrition Service, 2022). Delayed entry into prenatal care (Rubenstein et al., 2020) was also reported in women with intellectual disability.

Outcomes of pregnancy in women with intellectual disability and their infants

A total of 24 obstetric outcomes that reported maternal pregnancy and postnatal variables were recorded. For this review, they are organised into three groups: those occurring during pregnancy ('pregnancy complications'), during labour ('labour and birth variables' e.g. type of delivery), and during the postnatal period ('postnatal outcomes') (Table 2).

Pregnancy complications

In pregnancy, women with intellectual disability had higher risks of urinary tract infection (Fairthorne et al., 2020) and gestational hypertension (Rubenstein et al., 2020) compared to women without intellectual disability. In contrast, findings on pre-eclampsia, and gestational diabetes in women with and without intellectual disability were mixed. Two studies reported higher risks of pre-eclampsia (Fairthorne et al., 2020; Mueller et al., 2019) in women with intellectual disability, however no significant group differences in pre-eclampsia rates were reported by Goldacre et al. (2015). Similarly, higher rates of gestational diabetes in women with intellectual disability were reported by Mueller et al. (2019) while there was also evidence for no difference (Fairthorne et al., 2020; Rubenstein et al., 2020).

Labour and birth variables

Four studies reported higher rates of caesarean delivery in women with intellectual disability (Gleason et al., 2023; Höglund et al., 2012a; Höglund et al., 2012b; Rubenstein et al., 2021) while three studies reported no significant difference (Fairthorne et al., 2020; Goldacre et al., 2015; Mueller et al., 2019).

Induced births (Fairthorne et al., 2020; Mueller et al., 2019; Rubenstein et al., 2020) and forceps delivery (Goldacre et al., 2015)) were not associated with maternal intellectual disability. Women with intellectual disability had increased risk of postpartum haemorrhage (Fairthorne et al., 2020).

Delivery hospitalisation of more than three days (Mueller et al., 2019) and discharge to a place other than their usual home, such as another care facility, were more common amongst those with intellectual disability (Höglund et al., 2012a).

Offspring outcomes

A total of 46 birth, neonatal and infant outcomes were recorded, with many measures only reported in a single study.

Birth and neonatal outcomes

There was evidence of higher rates of preterm birth for women with intellectual disability (Fairthorne et al., 2020; Gleason et al., 2023; Goldacre et al., 2015; Höglund et al., 2012a; Höglund et al., 2012b; Rubenstein et al., 2021); no significant differences were also evident in two studies (Hindmarsh et al., 2015; Mueller et al., 2019). Infants of women with intellectual disability were significantly more likely to be born extremely preterm, defined as less than 28 weeks' gestation (Gleason et al., 2023) and infants of women with intellectual disability were also found with higher rates of very preterm birth when defined as 28 to 31 weeks (Gleason et al., 2023) or 20 to 29 weeks (Höglund et al., 2012a; Höglund et al., 2012b). No significant differences were observed when very preterm birth was defined as <33 weeks (Fairthorne et al., 2020).

Higher prolonged gestation (Goldacre et al., 2015) was evident in one study, with three other studies indicating no significant differences (Höglund et al., 2012a; Höglund et al., 2012b, Rubenstein et al., 2020).

One study reported higher rates of perinatal death, defined as infant death between 28 weeks' gestation and one week of life, were evident in infants of women with intellectual disability (Höglund et al., 2012b).

Across studies, findings varied for association of intellectual disability with birthweight, small for gestational age neonates, rates of congenital malformation, Apgar scores (a measure of neonate condition immediately after birth), stillbirth, and neonatal deaths. Low birthweight, when defined as either <85% of median, <2500g, or <10th percentile of gestational age, was significantly higher in infants of women with intellectual disability (Fairthorne et al., 2020; Gleason et al., 2023; Goldacre et al., 2015), although two studies also reported no significant difference (Hindmarsh et al., 2015; Mueller et al., 2019). While higher rates of small for gestational age were reported (Gleason et al., 2023; Höglund et al., 2012b; Mueller et al., 2019; Rubenstein et al., 2021), non-significant group differences were also evident (Goldacre et al., 2015).

Intellectual disability was not associated with rates of large for gestational age (Gleason et al., 2023; Höglund et al., 2012b; Mueller et al., 2019) and fetal distress in labour (Fairthorne et al., 2020; Mueller et al., 2019).

The proportion of infants having a low Apgar score (<7), indicative of a need for neonate medical attention, was higher in women with intellectual disability (Gleason et al., 2023; Höglund et al., 2012b), although there was also evidence for no significant difference (Fairthorne et al., 2020; Goldacre et al., 2015). Similarly, while Gleason et al. (2023) reported infants of women with intellectual disability had a higher risk of congenital malformations, other studies reported no significant difference (Höglund et al., 2012b; Mueller et al., 2019). Höglund et al. (2012b) found higher rates of stillbirth in infants of women with intellectual disability, but this was not a consistent finding (Gleason et al., 2023; Goldacre et al., 2015).

Two studies reported higher rates of neonatal death within the first 28 days of life (Gleason et al., 2023; Höglund et al., 2012b), but no significant difference was observed in one paper (Goldacre et al., 2015). One study reported higher rates of admission to the Neonatal Intensive Care Unit (NICU) in infants of women with intellectual disability (Gleason et al., 2023) but this finding was not replicated in other studies (Hindmarsh et al., 2015; Mueller et al., 2019).

Infant outcomes

Infants of women with intellectual disability were more likely to have longer hospitalisation periods of more than 2 or 3 days (Mueller et al., 2019; Hindmarsh et al., 2015). They were less likely to be breastfeeding at discharge (e.g. 33% infants born to women with intellectual disability were breastfed versus 70% of infants born to women without intellectual disability; Goldacre et al., 2015) (Mueller et al., 2019) or by one month (Hindmarsh et al, 2015).

Lower scores on the positive child health indicator at 9 months of age (a composite measure of being immunised, breastfed >1 month, and living with a non-smoking

mother) were reported in infants of women with intellectual disability, who also had higher rates of fine motor delay (Hindmarsh et al., 2015).

There were no overall differences in rates of hospitalization within the first nine months (Hindmarsh et al., 2015) or in the first two years post-delivery (Mueller et al., 2019), in gross motor delay (Hindmarsh et al., 2015), and infant temperament (Hindmarsh et al., 2015) between infants of women with and without intellectual disability.

Discussion

The aim of this review was to investigate the pregnancy and postnatal outcomes of women with intellectual disability and their infants. Nine articles met eligibility criteria; each used varying methodologies and measures to report a range of maternal pregnancy, labour, and neonatal outcomes. Later infant outcomes (up to 12 months of life) were not reported by most studies. Overall results indicate an increased risk of adverse obstetric and neonatal outcomes in mothers with intellectual disability and their infants. For obstetric outcomes, higher rates of urinary tract infection, gestational hypertension, postpartum haemorrhage, longer duration of delivery hospitalisation, and being discharged to a place other than home, were reported in women with intellectual disability compared with those without intellectual disability. Infants of women with intellectual disability were at higher risk of being born prematurely, dying in the perinatal period, spending longer in hospital, were less likely to be breastfed at discharge, received lower scores on the positive child health indicator, than their counterparts born to women without intellectual disability. However, the included articles were not concordant in reporting outcomes which limits direct comparisons, and results need to be interpreted with caution owing to the small number of studies.

Observed differences in findings between studies may, in part, be explained by methodological differences. First, included studies used data collected from different time periods; for example, Goldacre et al. (2015) reported findings from achieved data spanning births in the years 1970-1989, whereas Rubenstein et al (2020 and 2021) and Gleason et al (2023) used data gathered from 2000 onwards. General changes in

obstetric practices such as in the rate of caesarean delivery (Angolile et al., 2023), may account for differences in some results, though disparities between those with and without intellectual disability should not be influenced. Second, differences in location from which study samples were drawn could also impact outcomes as standard obstetric practices may differ by region. Third, it is likely that some studies were under-powered to detect a difference in rates of less common outcomes (e.g. stillbirth), and therefore the observed trends did not reach statistical significance. Moreover, groups with intellectual disability contained a much smaller number of individuals than their comparator group without intellectual disability. Fourth, studies may not have adjusted for all potential confounders in the relationship between intellectual disability and obstetric or neonatal outcomes (e.g. ethnicity and the presence of co-morbid health conditions) meaning that factors other than the presence of intellectual disability may influence some of the results seen.

Our review is the first of which we are aware that investigates pregnancy outcomes specifically in women with intellectual disability. Whilst overall findings align with existing literature that demonstrates a higher risk of adverse perinatal outcomes in women with any disability (Tarasoff et al, 2020), restricting our inclusion criteria to those with intellectual disability exposes the specific health needs of this group and can inform the development of interventions to reduce health inequalities.

Several underlying mechanisms are likely to play a role in the health disparities we have observed. Existing (pre-conception) co-morbidities and unhealthy lifestyle behaviours such as diabetes, obesity, poor diet and physical inactivity are more prevalent in people with intellectual disability (O'Leary et al, 2018) which could affect health in pregnancy. Women with intellectual disability have limited access to both informal and formal education about reproductive health including family planning and contraception (Ransohoff et al, 2022; Greenwood and Wilkinson, 2013). There is some evidence that they present to ante-natal services later in the course of their pregnancy (Ransohoff et al, 2022), which limits opportunities for advice and support. Numerous barriers to accessing appropriate and timely healthcare by people with intellectual disability have been identified, including physical inaccessibility, difficulties navigating healthcare

services and booking systems, a lack of adapted communication and information resources (Homeyard et al, 2016; Saeed et al, 2022), and inadequate training of healthcare providers (Castell and Kroese, 2016; Malouf et al, 2016). Despite progress in social attitudes towards disability and changes in policy, some people, including healthcare staff, continue to hold negative attitudes towards people with intellectual disability and their abilities as parents which can result in discrimination and, potentially, exclusion from appropriate care (Hoglund and Larsson, 2012; Malouf et al, 2016; Potvin et al, 2019). On a wider scale, people with intellectual disability may experience social challenges that impact their preparation and caring for a new baby, including poverty and lack of a support network beyond health services (Emerson & Hatton, 2009; McGarry et al, 2016).

Strength and limitations of this review

To the best of our knowledge, this systematic review is the first to synthesise the current literature on the pregnancy and postnatal outcomes of women with intellectual disability and their infants. We included a broad range of measures and outcomes and did not include limits on time or location of studies, leading to a comprehensive review. Nevertheless, there are limitations to this review. We looked at outcomes within the first 12 months of child development and therefore any findings concerning later developmental or longer-term outcomes were not included. The relatively small number of eligible studies may also be attributed to low levels of research attention paid to the intellectual disability population; although people with intellectual disability are a small minority of the total population, they are more likely to use health services and experience significant health inequalities across the lifespan, and we therefore advocate additional work to better understand maternity needs and improve care in this group. This may be due to difficulties gaining consent, gaining ethical approval for studies, or varying intellectual abilities creating challenges in recruitment (Lennox et al., 2005; Mulhall et al., 2021). Due to substantial heterogeneity in the range of variables reported and differences in measures, a meta-analysis of outcomes was not possible and we rely on a narrative synthesis and comparison.

Research and clinical implications

Our findings provide an initial understanding of the vulnerabilities and needs of women with intellectual disability during the perinatal period. The findings of this review point to avoidable inequalities in maternity care experienced by women with intellectual disability in much the same way as they experience inequalities in other areas of healthcare (White et al, 2023; Whittle et al, 2018). Further research on the association of maternal intellectual disability with maternal pregnancy and infant outcomes is clearly warranted and should investigate the mechanisms by which adverse outcomes are mediated, and what population- or individual-level health interventions are effective. This may include, for example, improving the delivery of adapted sexual and reproductive healthcare information, providing a consistent level of training for healthcare staff (e.g. via the continued roll-out of the Oliver McGowan Mandatory Training in learning disability and autism in England (NHS England, n.d.) or other evidence-based programmes specific to maternity care (Cox et al, 2024)), promoting pre-conception health and targeting modifiable risk factors in women of childbearing age by public health or more targeted measures (e.g. by inclusion in the annual learning disability health check (Buszewicz et al, 2014)), and providing better, more individualised support across the maternity care pathway (e.g. by promoting integrated care between maternity services, community learning disability teams, and hospital-based learning disability liaison nurses). Social care services also need to be recruited to ensure that women with intellectual disability have the right type and degree of support to be successful parents, including material resources and access to parent training interventions, when required (Coren et al. 2018).

Intellectual disability must be recognised and accurately recorded in maternity settings; not only will this alert and direct healthcare staff to provide reasonable adjustments to care but will also enable better national surveillance and large-scale research using routinely-collected health data (NHS Digital, 2023).

Owing to a myriad of risk factors more prevalent in people with intellectual disability, rates of mental illness are greater than in those without intellectual disability (Mazza et

al., 2020) and there is evidence that this extends to perinatal mental illness (Brown et al, 2022). It was notable that maternal mental health status was not measured in any of the studies included in this review; additional research should examine whether women with intellectual disability specifically are at increased risk of postnatal mental health problems and the additional support they may require.

In order to develop the evidence-base further, it would be helpful if researchers, with input from people with intellectual disability and their carers and supporters, agree a common outcome set to employ in future studies to enable study findings to be compared and combined more easily; this is likely to require international collaboration. Finally, future research should examine obstetric and neonatal outcomes in participants from less economically developed countries, and how best healthcare systems that are less well-resourced can deliver the most effective care to women with intellectual disability and their infants.

References

Angolile, C. M., Max, B. L., Mushemba, J., & Mashauri, H. L. 2023. Global increased cesarean section rates and public health implications: A call to action. *Health Science reports,* 6(5), e1274. Doi: 10.1002/hsr2.1274

Baines, S., Emerson, E., Robertson, J., & Hatton, C. 2018. Sexual activity and sexual health among young adults with and without mild/moderate intellectual disability. *BMC Public Health,* 18, 1-12. Doi: 10.1186/s12889-018-5572-9

Brown, H. K., Cobigo, V., Lunsky, Y., & Vigod, S. N. 2017. Maternal and offspring outcomes in women with intellectual and developmental disabilities: A population based cohort study. *BJOG: An International Journal of Obstetrics & Gynaecology,* 124(5), 757-765. Doi: 10.1111/1471-0528.14235

Brown, H. K., Lunsky, Y., Wilton, A. S., Cobigo, V., & Vigod, S. N. 2016. Pregnancy in women with intellectual and developmental disabilities. *Journal of Obstetrics and Gynaecology Canada,* 38(1), 9-16. Doi: 10.1016/j.jogc.2015.10.004

Brown, H. K., Vigod, S. N., Fung, K., Chen, S., Guttmann, A., Havercamp, S.M., Parish, S.L., Ray, J.G., Lunsky, Y. 2022. Perinatal mental illness among women with disabilities: a population-based cohort study. *Social Psychiatry and Psychiatric Epidemiology.* 57, 2217-2228. Doi: 10.1007/s00127-022-02347-2

Buszewicz, M., Welch, C., Horsfall, L., Nazareth, I., Osborn, D., Chauhan, U., Hoghton, M., Cooper, S-A., Moulster, G., Hithersay, R., Hunter, R., Heslop, P., Courtenay, K., Strydom, A. 2014. Assessment of an incentivised scheme to provide annual health checks in primary care for adults with intellectual disability: a longitudinal cohort study. *The Lancet Psychiatry,* 1(7), 522-530. Doi: 10.1016/S2215-03te66(14)00079-0

Castell, E., & Kroese, B. S. 2016. Midwives' experiences of caring for women with learning disabilities – a qualitative study. *Midwifery,* 36, 35-42. Doi: 10.1016/j.midw.2016.02.001

Coren, E., Ramsbotham, K, Gschwandtner, M. 2018. Parent training interventions for parents with intellectual disability. *Cochrane Database of Systematic Reviews.* 7, CD007987. Doi: 10.1002/14651858.CD007987.pub3

Cox, R., Stenfert Kroese, B., & McGarry, A. 2015. Pregnancy, birth and postnatal support for women with intellectual disabilities: The CanDo Doula model. *International Journal of Birth & Parent Education, 2*(3).

Cox, A., Tobutt, D., Harris, J., Watkin, S., Eynon, C., Matuska, G. 2024. Learning disability awareness training for undergraduate midwifery students: multi-method evaluation of a co-produced and co-delivered educational intervention in England. *Nurse Education Today,* 140, 106289. Doi: 10.1016/j.nedt.2024.106289

Fairthorne, J., Bourke, J., O'Donnell, M., Wong, K., De Klerk, N., Llewellyn, G., & Leonard, H. 2020. Pregnancy and birth outcomes of mothers with intellectual disability and their infants: Advocacy needed to improve well-being. *Disability and Health Journal,*13(2), 100871. Doi: 10.1016/j.dhjo.2019.100871

Food and Nutrition Service. 2022. *Special Supplemental Nutrition Program for Women, Infants, and Children (WIC).* U.S. Department of Agriculture, Food and Nutrition Service. https://www.fns.usda.gov/wic

Gleason, J. L., Grewal, J., Chen, Z., Cernich, A. N., & Grantz, K. L. 2023. Risk of adverse neonatal outcomes among pregnant women with disabilities. *International Journal of Epidemiology,* 52(1), 203–213. Doi: 10.1093/ije/dyac183

Goldacre, A. D., Gray, R., & Goldacre, M. J. 2015. Childbirth in women with intellectual disability: characteristics of their pregnancies and outcomes in an archived epidemiological dataset. *Journal of Intellectual Disability Research,* 59(7), 653-663. Doi: https://doi.org/10.1111/jir.12169

Greenwood, N. W., & Wilkinson, J. 2013. Sexual and reproductive health care for women with intellectual disabilities: a primary care perspective. *International Journal of Family Medicine,* Doi: 10.1155/2013/642472

Harrison, R. A., Bradshaw, J., Forrester-Jones, R., McCarthy, M., & Smith, S. 2021. Social networks and people with intellectual disabilities: A systematic review. *Journal of Applied Research in Intellectual Disabilities,* 34(4), 973-992. Doi: 10.1111/jar.12878

Havercamp, S. M., and Scott, H. M. 2015. National health surveillance of adults with disabilities, adults with intellectual and developmental disabilities, and adults with no disabilities. *Disability and Health Journal,* 8(2), 165-172. Doi: 10.1016/j.dhjo.2014.11.002

Hindmarsh, G., Llewellyn, G., & Emerson, E. 2015. Mothers with intellectual impairment and their 9-month-old infants. *Journal of Intellectual Disability Research,* 59(6), 541-550. Doi: 10.1111/jir.12159

Höglund, B., & Larsson, M. 2012. Struggling for motherhood with an intellectual disability – a qualitative study of women's experiences in Sweden. *Midwifery*, 29(6), 698-704. Doi: 10.1016/j.midw.2012.06.014

Höglund, B., & Larsson, M. 2014. Professional and social support enhances maternal well-being in women with intellectual disability – a Swedish interview study. *Midwifery,* 30(11), 1118-1123. Doi: 10.1016/j.midw.2014.03.018

Höglund, B., Lindgren, P., & Larsson, M. 2012a. Pregnancy and birth outcomes of women with intellectual disability in Sweden: a national register study. *Acta obstetricia et gynecologica Scandinavica,* 91(12), 1381-1387. Doi: 10.1111/j.1600-0412.2012.01509.x

Höglund, B., Lindgren, P., & Larsson, M. 2012b. Newborns of mothers with intellectual disability have a higher risk of perinatal death and being small for gestational age. *Acta obstetricia et gynecologica Scandinavica,* 91(12), 1409-1414. Doi: 10.1111/j.1600-0412.2012.01537.x

Homeyard, C., Montgomery, E., Chinn, D., & Patelarou, E. 2016. Current evidence on antenatal care provision for women with intellectual disabilities: A systematic review. *Midwifery,* 32, 45-57. Doi: 10.1016/j.midw.2015.10.002. Doi: 10.1016/j.midw.2015.10.002

Horner-Johnson, W., Darney, B. G., Kulkarni-Rajasekhara, S., Quigley, B., & Caughey, A. B. 2016. Pregnancy among US women: differences by presence, type, and complexity of disability. *American Journal of Obstetrics and Gynecology,* 214(4), 529-e1. Doi: 10.1016/j.ajog.2015.10.929

Horner-Johnson, W., Garg, B., Darney, B. G., Biel, F. M., & Caughey, A. B. 2022. Severe maternal morbidity and other perinatal complications among women with physical, sensory, or intellectual and developmental disabilities. *Paediatric and Perinatal Epidemiology,* 36(5), 759-768. Doi: 10.1111/ppe.12873

Johnson, K., Traustadottir, R., Harrison, L., Hillier, L., and Sigurjonsdottir, H. B. 2001. The possibility of choice: women with intellectual disabilities talk about having children. In: Priestley, M. (ed.) *Disability and the life course: global perspectives* (pp.206-218). Cambridge University Press, Cambridge, England.

Louw, J. S., Kirkpatrick, B, Leader, G. 2020. Enhancing social inclusion of young adults with intellectual disabilities: a systematic review of original empirical studies. *Journal of Applied Research in Intellectual Disabilities,* 3(5), 793-807. Doi: 10.1111/jar.12678

Malouf, R., McLeish, J., Ryan, S., Gray, R., & Redshaw, M. 2017. 'We both just wanted to be normal parents': a qualitative study of the experience of maternity care for women with learning disability. *BMJ Open,* 7(3), e015526. Doi: 10.1136/bmjopen-2016-015526

Maulik, P. K., Mascarenhas, M. N., Mathers, C. D., Dua, T., & Saxena, S. 2011. Prevalence of intellectual disability: a meta-analysis of population-based studies. *Research in Developmental Disabilities,* 32(2), 419-436. Doi: 10.1016/j.ridd.2010.12.018

Mazza, M. G., Rossetti, A., Crespi, G., & Clerici, M. 2020. Prevalence of co-occurring psychiatric disorders in adults and adolescents with intellectual disability: A systematic review and meta-analysis. *Journal of Applied Research in Intellectual Disabilities,* 33(2), 126-138. Doi: 10.1111/jar.12654

McGarry, A., Stenfert Kroese, B., & Cox, R. 2016. How do women with an intellectual disability experience the support of a doula during their pregnancy, childbirth and after the birth of their child? *Journal of Applied Research in Intellectual Disabilities,* 29(1), 21-33. Doi: 10.1111/jar.12155

Mueller, B. A., Crane, D., Doody, D. R., Stuart, S. N., & Schiff, M. A. 2019. Pregnancy course, infant outcomes, rehospitalization, and mortality among women with intellectual disability. *Disability and Health Journal,* 12(3), 452-459. Doi: 10.1016/j.dhjo.2019.01.004

Mulhall, P., Taggart, L., McAloon, T., & Coates, V. 2021. Challenges to conducting randomised controlled trials with adults with intellectual disabilities: Experiences of international experts. *Journal of Applied Research in Intellectual Disabilities,* 34(3), 891-904. Doi: 10.1111/jar.12838

National Heart, Lung, and Blood Institute. 2019. Study Quality Assessment Tools. Available at: https://www.nhlbi.nih. gov/health-topics/study-quality-assessment-tools.

Neiger, R. 2017. Long-term effects of pregnancy complications on maternal health: a review. *Journal of Clinical Medicine,* 6(8), 76. Doi: 10.3390/jcm6080076

NHS Digital. 2005. Adults with Learning Difficulties in England, 2003-2004. *NHS England*. https://digital.nhs.uk/data-and-information/publications/statistical/adults-with-learning-difficulties-in-england/adults-with-learning-difficulties-in-england-2003-2004

NHS Digital 2023. *Reasonable adjustment flag.* Available at: https://digital.nhs.uk/services/reasonable-adjustment-flag

NHS England. n.d. *The Oliver McGowan Mandatory Training on Learning Disability and Autism*. Retrieved May 19, 2024. https://www.hee.nhs.uk/our-work/learning-disability/current-projects/oliver-mcgowan-mandatory-training-learning-disability-autism

Office of Population Censuses and Surveys. 1980. *Classification of Occupations 1980*. Her Majesty's Stationery Office, London.

O'Hara, M. W., & Wisner, K. L. 2014. Perinatal mental illness: definition, description and aetiology. *Best Practice & Research Clinical Obstetrics & Gynaecology,* 28(1), 3-12. Doi: 10.1016/j.bpobgyn.2013.09.002

O'Leary, L., Taggart, L., Cousins, W. 2018. Healthy lifestyle behaviours for people with intellectual disabilities: an exploration of organizational barriers and enablers. *Journal of Intellectual Disability Research,* 31(S1), 122-135. Doi: 10.1111/jar.12396

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M.,

Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., ... Moher, D. 2021. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ,* 372. doi:10.1136/bmj.n71

Potvin, L. A., Barnett, B.M., Brown, H.K., Cobigo, V. 2019. "I didn't need people's negative thoughts": women with intellectual and developmental disabilities reporting attitudes toward their pregnancy. *Canadian Journal of Nursing Research,* 51(3), 154-167. Doi: 10.1177/0844562118819924

Ransohoff, J. I., Kumar, P. S., Flynn, D., & Rubenstein, E. 2022. Reproductive and pregnancy health care for women with intellectual and developmental disabilities: A scoping review. *Journal of Applied Research in Intellectual Disabilities,* 35(3), 655-674. Doi: 10.1111/jar.12977

Rubenstein, E., Ehrenthal, D. B., Mallinson, D. C., Bishop, L., Kuo, H-H., & Durkin, M. 2020. Pregnancy complications and maternal birth outcomes in women with intellectual and developmental disabilities in Wisconsin Medicaid. *PLoS ONE,* 15(10), e0241298. Doi: 10.1371/journal.pone.0241298

Rubenstein, E., Ehrenthal, D. B., Mallinson, D. C., Bishop, L., Kuo, H. H., & Durkin, M. S. 2021. Birth outcomes affecting infants of mothers with intellectual and developmental disabilities. *Paediatric and Perinatal Epidemiology,* 35(6), 706-716. Doi: 10.1111/ppe.12765

Saeed, G., Brown, H. K., Lunsky, Y., Welsh, K., Proulx, L., Havercamp, S., & Tarasoff, L. A. 2022. 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. *BMC Pregnancy and Childbirth,* 22(1), 364. Doi: 10.1186/s12884-022-04691-2

Scior, K., Hamid, A., Hastings, R., Werner, S., Belton, C., Laniyan, A., Patel, K., Groce, N., Kett, M. 2016. Consigned to the margins: a call for global action to challenge intellectual disability stigma. *The Lancet Global Health*. 4(5), E294-E295. Doi: 10.1016/S2214-109X(16)00060-7

Stein, A., Pearson, R. M., Goodman, S. H., Rapa, E., Rahman, A., McCallum, M., Howard, L. M., & Pariante, C. M. 2014. Effects of perinatal mental disorders on the fetus and child. *Lancet,* 384(9956), 1800–1819. Doi: 10.1016/S0140-6736(14)61277-0

Tarasoff, L. A., Ravindran, S., Malik, H., Salaeva, D., & Brown, H. K. 2020. Maternal disability and risk for pregnancy, delivery, and postpartum complications: a systematic review and meta-analysis. *American Journal of Obstetrics and Gynecology,* 222(1), 27-e1. Doi: 10.1016%2Fj.ajog.2019.07.015

Tilley, E., Walmsley, J., Earle, S., & Atkinson, D. 2012. 'The silence is roaring': sterilization, reproductive rights and women with intellectual disabilities. *Disability & Society,* 27(3), 413-426. Doi: 10.1080/09687599.2012.654991

White, A., Sheehan, R., Ding, J., Roberts, C., Magill, N., Keagan-Bull, R., Carter, B., Chauhan, U., Tuffrey-Wijne, I., Strydom, A. 2023. LeDeR annual report. Learning from lives and deaths: people with a learning disability and autistic people. King's College London. Available at: kcl.ac.uk/ioppn/assets/fans-dept/leder-2022-v2.0.pdf

Whittle, E. L., Fisher, K. R., Reppermund, S., Lenroot, R, Trollor, J. 2018. Barriers and enablers to accessing mental health services for people with intellectual disability: a scoping review. *Journal of Mental Health Research in Intellectual Disabilities*, 11(1), 69-102. Doi: 10.1080/19315864.2017.1408724

Wolfensberger, W. P., Nirje, B., Olshansky, S., Perske, R., & Roos, P. 1972. The principle of normalisation in human management services. National Institute of Mental Retardation.

World Health Organization. 2019. International statistical classification of diseases and related health problems (11th ed.). Available at: https://icd.who.int/

Yazdkhasti, M., Pourreza, A., Pirak, A., & Fatemeh, A. B. D. I. 2015. Unintended pregnancy and its adverse social and economic consequences on health system: a narrative review article. *Iranian Journal of Public Health,* 44(1), 12-21.

Table 1 Study and sample characteristics

Reference, country, study design	Recruitment	Maternal socio-demographic characteristics		Health markers	Prenatal care
		Demographic	**Socio-economic**		
Fairthorne et al (2020) Australia Cross-sectional	All midwife-attended deliveries in Western Australia between 1983 and 2012 **Sample** 943 women with ID (731 non-Aboriginal, 212 Aboriginal) 7,800 women without ID (6,017 non-Aboriginal, 1,783 Aboriginal)	**Age** - ID group: 0.2% aged 12-14, 22.2% ≤19 years, 60.7% 20-29 years, 16.0% 30-39 years, 1.1% ≥40 years - Comparison group was age-matched **Race/ethnicity** - ID group: 77.5% non-Aboriginal and 22.5% Aboriginal Australian - Comparison group: 77.1% non-Aboriginal and 22.9% Aboriginal Australians	**Marital status** <u>Non-Aboriginal women</u> - ID group: 53.8% single - Comparison group: 77.9% single - RRR 2.32, 95%CI (2.03, 2.66) <u>Aboriginal women</u> - ID group: 37.3% single - Comparison group: 42.2% single - RRR 1.23, 95%CI (0.92, 1.65) **Socioeconomic status**[b]	**Smoking** <u>Non-Aboriginal women</u> - ID group: 29.7% - Comparison group: 18.4% - RRR of 1.87, 95%CI (1.51, 2.31) <u>Aboriginal women</u> - ID group: 49.0% - Comparison group: 44.4% - RRR 1.21 95%CI (0.87, 1.68)	N/R

			<u>Non-Aboriginal women</u> - ID group: 27.5% lowest quintile - Comparison group: 12.3% lowest quintile - RRR 2.24 (95%CI 1.86, 2.70) <u>Aboriginal women</u> - ID group: 35.4% lowest quintile - Comparison group: 31.9% lowest quintile - RRR 1.16 (95%CI 0.84, 1.60)		
Gleason et al (2023) USA Cross-sectional	All registered births across 19 hospitals in 12 US states between 2002 and 2008 **Sample** 91 women with ID 221,252 women with no disabilities	**Age** - ID group: mean 25.2 years (SD = 7.1) - Comparison group: mean 27.6 years (SD = 6.2) **Race/ethnicity**	**Marital status** N/R **Socioeconomic status** N/R	**BMI** - ID group: mean 25.6kg/m^2 (SD = 6.0) - Comparison group: mean 25.4kg/m^2 (SD = 6.2) **Smoking** - ID group: 12.1%	N/R

		- ID group: 49.4% White, 27.5% Black, 14.3% Hispanic, 0% Asian/Pacific Islander, 0% other/multi-racial, 8.8% unknown - Comparison group: 49.3% White, 22.5% Black, 17.5% Hispanic, 4.1% Asian/Pacific Islander, and 6.5% other/multi-racial, 0.1% unknown		- Comparison group: 6.6% **Chronic disease/existing medical conditions**[b] - ID group: 38.5% - Comparison group: 17.7% **Parity** - ID group: 56% had no prior births, and 44% had ≥1 - Comparison group: 39.8% had no prior births, 60.2% had ≥1	
Goldacre et al (2015) UK Cross-sectional	Maternity data from Oxfordshire and west Berkshire between 1970 and 1989 **Sample** 217 births to women with ID 244,790 births to women without ID	**Age** - ID group: 57.0% 14-24 years, 38.5% 25-34 years, and 4.7% ≥35 years - Comparison group: 34.9% aged 14- 24, 57.6% aged 25-34, and 7.5% were aged ≥35	**Marital status** - ID group: 58.3% married - Comparison group: 90.6% married - Group difference p<0.001 **Social class**[d]	**Weight** - ID group: 84.6% ≤ 11st, 2.6% ≥ 15st. - Comparison group: 88.0% ≤ 11st, 1.7% ≥ 15st. - Group difference p=0.73 **Smoking** - ID group: 53.7% smokers	N/R

		- Group difference p<0.001 **Race/ethnicity** N/R	- ID group: 31.6% lowest quintile - Comparison group: 5.1% lowest quintile - Group difference p<0.001	- Comparison group: 22.7% smokers - Group difference p<0.001 **Parity** - ID group: 34.6% had no prior births, 30.4% had 1, 17.5% had 2, and 17.5% had ≥3 - Comparison group: 42% had no prior births, 35.9% had 1, 14.5% had 2, and 7.6% had ≥3 - Group difference p<0.001	
Hindmarsh et al. (2015) UK Cross-sectional	Children born between September 2000 and August 2001 (England and Wales) or between November 2000 and January 2002 (Scotland and Northern Ireland) **Sample** 74 women with II 18,115 women without II	**Age** - II group: 36.5% <20 years - Comparison group: 21.2% <20 years OR 2.1 (95%CI 1.3, 3.4) **Race/ethnicity** N/R	**Marital status** - II group: 40.5% married - Comparison group: 59.5% married - OR 2.2 (95%CI 1.4, 3.4) **Socioeconomic status**[e] - II group: 62.2% income poverty	**BMI** No significant difference between women with II and those in comparison group (detailed results N/R) **Smoking** - II group: 55.4% - Comparison group: 30.3% - OR N/R (95%CI 1.8, 4.5)	N/R

			- Comparison group: 35.9% income poverty - OR 2.9 (95%CI 1.8, 4.7)	**Longstanding illness/disability/infirmity** - II group: 31.1% - Comparison group: 21.0% - OR N/R (95%CI 1.0, 2.8)	
Höglund et al. (2012a) and Höglund et al (2012b) Sweden Cross-sectional	Births in Sweden from 1999 to 2007 **Sample** 326 infants born to women with ID 340,624 infants born to women without ID	**Age** - ID group: mean 24.20 years (range 16-46) - Comparison group: mean 28.28 years (range 11-55) - p<0.001 **Race/ethnicity** N/R	**Marital status** N/R **Socioeconomic status** N/R	**BMI (mean)** - ID group: mean 25.4kg/m^2 (range 15.2-45.9) - Comparison group: mean 24.0kg/m^2 (range 15.0-63.2) - Group difference p=0.015 **BMI (≥30kg/m^2)** - ID group: ≥30kg/m^2 20.1% - Comparison group: ≥30kg/m^2 8.6% - Statistical comparison N/R **Smoking** - ID group: 27.9% - Comparison group: 7.9%	N/R

				- RR 3.5 (95%CI 2.9, 4.4)	
Mueller et al. (2019) USA Cross-sectional	Hospital records and birth and fetal death certificates in Washington state from 1987 to 2012 **Sample** 103 women with ID 1,034 women without ID	**Age** - ID group: 55.4% 18-24 years, 36.0% 25-34 years, 8.7% aged ≥35 - Comparison group: 29.6% 18-24 years, 56.7% 25-34 years, 13.7% ≥35 years **Race/ethnicity** - ID group: 83.3% White, 3.9% Black, and 12.7% other - Comparison group: 78.0% White, 3.7% Black, and 18.3% other	**Marital status** - ID group: 73.3% unmarried - Comparison group: 25.0% unmarried - OR 8.52 (95%CI 5.34, 13.58) **Socioeconomic status** N/R	**BMI** - ID group: 32.1% <25.0kg/m^2, 42.9% 25.0-29.9 kg/m^2, 25.0% ≥30.0 kg/m^2. - Comparison group: 49.3% <25.0 kg/m^2, 25.5% 25.0-29.9 kg/m^2, 25.2% ≥30.0 kg/m^2. - OR BMI ≥30.0 kg/m^2 0.60 (95%CI 0.22-1.60) **Smoking** - ID group: 29.6% - Comparison group: 14.9% - OR smoking 2.43 (95%CI 1.51, 3.90) **Parity** - ID group: 68.9% no prior births, 14.6% 1 prior birth, 16.5% ≥2 prior births	**Medicaid/Medicare** - ID group: 89.3% - Comparison group: 36.9% - OR 14.74 (95%CI 7.77, 27.96) **Kotelchuck Index of prenatal care**[c] - ID group: 31.0% had inadequate care - Comparison group: 12.3% had inadequate care - RR inadequate care 2.48 (95%CI 1.67, 3.70) **The Special Supplemental Nutrition Program for Women, Infants, and Children** - ID group: 70.4% - Comparison group: 42.4% - OR 3.23 (95%CI 1.37, 7.61)

				- Comparison group: 39.2% no prior births, 34.2% 1 prior birth,26.7% ≥2 prior birth s - OR no prior births 3.44 (95%CI 2.23, 5.33) **Gravidity** - ID group: 50.5% 0 prior pregnancies, 20.8% 1 prior pregnancy, 28.7% ≥2 prior pregnancies - Comparison group: 28.9% 0 prior pregnancies, 28.9% 1 prior pregnancy, 42.3% ≥2 prior pregnancies - OR no prior pregnancies 2.52 (95%CI 1.67, 3.81)	
Rubenstein et al (2020) USA Cross-sectional	Birth records in Wisconsin from 2007 to 2016 **Sample** 552 women with ID 176,665 women without ID	**Age** - ID group: mean 25.3 years (SD 6.0) - Comparison group: 26.3 years (SD 5.7) **Race/ethnicity**	**Marital status** - ID group: 13.6% married - Comparison group: 32.8% married **Socioeconomic status** N/R	**BMI** - ID group: 6.7% underweight, 28.5% normal weight, 22.7% overweight, 42.7% obese - Comparison group: 3.1% underweight, 37.2% were of normal weight, 26.0%, overweight, 33.7% obese	**Trimester prenatal care began** - ID group: 65.4% first trimester, 25.7% second, 6.0% third, 3.0% received no prenatal care - Comparison group: 73.4% first trimester, 21.6% second, 4.1% third, 0.8% received no prenatal care

		- ID group: 58.3% White, 33.8% Black, and 7.9% other - Comparison group: 73.4% White, 18.5% Black, and 8.1% other		RR obesity 1.38 (95% CI 1.2, 1.6) **Smoking** - ID group: 31.6% - Comparison group: 26.6% - RR 1.11 (95%CI 0.9, 1.3)	- RR prenatal care in first trimester 0.89 (95%CI 0.8, 1.0) **The Special Supplemental Nutrition Program for Women, Infants, and Children** - ID group: 86.2% - Comparison group: 66.6% - RR 1.31 (95%CI 1.2, 1.4)
Rubenstein et al (2021) USA Cross-sectional	Birth records from 2007 to 2016 in Wisconsin **Sample** 534 infants born to women with ID 265,699 infants born to women without ID	**Age** N/R **Race/ethnicity** N/R	**Marital status** N/R **Socioeconomic status** N/R	N/R	N/R

BMI, body mass index; CI, confidence interval; ID, intellectual disability; IDD, intellectual and developmental disabilities; II, intellectual impairment; NICU, Neonatal Intensive Care Unit; N/R, not reported; OR, odds ratio; RR, risk ratio; RRR, relative risk ratio; SD, standard deviation.

a. Based on the Index of Relative Socioeconomic Advantage and Disadvantage (IRSAD) and derived from the Australian Census data
b. Includes asthma, depression, anxiety, HIV, hypertension, renal disease, heart disease, pre-gestational diabetes, thyroid disease.
c. Also known as the Adequacy of Prenatal Care Utilization (APNCU) Index (based on the ratio of observed to expected number of prenatal visits)

d. Determined by the occupation of the mother
e. Income poverty defined by net equivalent household income below 60% national median

Table 2 Outcomes reported and findings of the included studies

Reference	Study outcomes reported		Study findings
	Maternal	**Offspring**	
Gleason et al (2023)	**Labour variables** Spontaneous pre-term birth Medically-indicated pre-term birth Caesarean delivery	**Birth & neonatal outcomes** Preterm birth ● <37 weeks ● 32-36 weeks Very preterm ● 28-31 weeks Extremely preterm ● <28 weeks Low birth weight ● <2500g Small for gestational age ● <10th percentile for gestational age Large for gestational age ● >90th percentile for gestational age Stillbirth Neonatal death	Women with ID had significantly higher rates of **caesarean delivery** (aRR=1.49, 95%CI 1.10, 2.01). No significant differences were found in rates of **spontaneous pre-term birth** (aRR=1.03, 95%CI 0.57, 1.85) or **medically-indicated pre-term birth** (aRR=1.05, 95%CI 0.61, 1.80) when compared to women without ID. For infants of women with ID, there were significantly higher rates of **preterm birth** (aRR=2.23, 95%CI 1.56, 3.20), **very preterm birth** (aRR=3.79, 95%CI 1.70, 8.46), **extremely preterm birth** (aRR=3.11, 95%CI 1.17, 8.31), **low birthweight** (aRR=2.34, 95%CI 1.58, 3.47), and **small for gestational age** (aRR=1.58, 95%CI 1.01, 2.48). No significant differences were found in rates of **large for gestational age** (aRR=1.07, 95%CI 0.55, 2.05). They were also significantly more likely to face birth complications including **resuscitation in delivery room** (aRR=3.19, 95%CI 1.43, 7.12), **respiratory distress syndrome** (aRR=2.88, 95%CI 1.60, 5.21), **apnoea** (aRR=2.46, 95%CI 1.17, 5.17), **necrotizing enterocolitis** (aRR=20.45, 95%CI 8.42, 49.69), **sepsis** (aRR=2.78, 95%CI 1.50, 5.19), **anaemia** (aRR=2.56, 95%CI 1.15, 5.71), **seizure** (aRR=16.60, 95%CI 6.17, 44.67), **congenital malformation** (aRR=2.54, 95%CI 1.51, 3.03),

		• Intrauterine death, intrapartum death, or death < 7 days Resuscitation in delivery room • Requiring continuous positive airway pressure (CPAP) or higher NICU admission **Infant outcomes** Respiratory distress syndrome, Apnoea, Transient tachypnoea, Asphyxia, Infective pneumonia, Aspiration, Necrotizing enterocolitis, Sepsis, Anaemia, Cardiomyopathy, Periventricular/ intraventricular haemorrhage, Intracerebral haemorrhage, Seizure, Retinopathy, Congenital malformation	as well as **neonatal deaths** (aRR=14.51, 95%CI 6.47, 32.57) and **NICU admission** (aRR=2.28, 95%CI 1.59, 3.26). Remaining outcomes showed no significant differences between infants of women with and without ID: **transient tachypnoea** (aRR=1.51, 95%CI 0.68, 3.36), **asphyxia** (aRR=3.12, 95%CI 0.44, 22.24), **infective pneumonia** (aRR= 1.63, 95%CI 0.23, 11.61), **aspiration** (aRR=3.86, 95%CI 0.96, 15.47), **cardiomyopathy** (aRR=0), **periventricular/ intraventricular haemorrhage** (aRR=2.55, 95%CI 0.64, 10.24), **intracerebral haemorrhage** (aRR=3.11, 95%CI 0.44, 22.22), **retinopathy** (aRR=3.01, 95%CI 0.75, 12.07), and **stillbirth** (aRR=2.18, 95%CI 0.31, 15.53).

Rubenstein et al (2021)	N/R	**Birth and neonatal outcomes** Preterm birth ● <37 weeks Small for gestational age ● ≤5th percentile ● ≤10th percentile	Infants of women with ID were significantly more likely to be born **preterm** (PR=1.64, 95%CI 1.42, 1.89), and **small for gestational age** where infants were **≤5th percentile of their gestational age** (PR=1.80, 95%CI 1.36, 2.37) and **≤10th percentile** (PR=1.59, 95%CI 1.31, 1.94).
Fairthorne et al (2020)	**Pregnancy complications** Pre-eclampsia Gestational diabetes UTI Pre-labour membrane rupture Antepartum haemorrhage Postpartum haemorrhage Shoulder dystocia Cephalopelvic disproportion	**Birth and neonatal outcomes** Preterm birth ● <37 weeks Very preterm ● <33 weeks Percentage of optimum birth weight ● <85% of median ● >115% of median Apgar score at 5 minutes ● Score <7 (low) Percentage of optimum head circumference ● <95% ● >105%	Non-Aboriginal women with ID were found significantly more at risk of **pre-eclampsia** (RRR=1.63, 95%CI 1.26, 2.11), **UTI** (RRR=1.79, 95%CI 1.35, 2.38), and **postpartum haemorrhage** (RRR=1.33, 95%CI 1.05, 1.68). There were no significant differences in **spontaneous labour** (RRR=0.95, 95%CI 0.83, 1.09)**, induced labour** (RRR=1.13, 95%CI 0.96, 1.31)**, caesarean delivery** (RRR=0.92, 95%CI 0.71, 1.20)**, gestational diabetes** (RRR=1.21, 95%CI 0.76, 1.92)**, pre-labour membrane rupture** (RRR=1.34, 95%CI 0.96, 1.86)**, antepartum haemorrhage** (RRR=1.18, 95%CI 0.80, 1.72)**, shoulder dystocia** (RRR=1.77, 95%CI 0.98, 3.16)**, cephalopelvic disproportion** (RRR=1.24, 95%CI 0.84, 1.82), and **persistent occipito-posterior** (RRR=0.81, 95%CI 0.44, 1.47) when compared to non-Aboriginal women without an ID. No significant differences in obstetric outcomes when comparing Aboriginal women with and without ID. Regardless of Aboriginal status, infants of women with ID were at significantly higher risks of **preterm birth** (non-Aboriginal RRR=1.52, 95%CI 1.13, 2.05; Aboriginal RRR=1.57, 95%CI 1.01, 2.44), **low birthweight** (non-Aboriginal RRR=1.50, 95%CI 1.20,

	Persistent occipito-posterior **Labour variables** Spontaneous labour Induced labour Caesarean delivery		1.88; Aboriginal RRR=1.56, 95%CI 1.11, 2.19) and **<95% of optimum head circumference** (non-Aboriginal RRR=1.32, 95%CI 1.02, 1.71; Aboriginal RRR=1.65, 95%CI 1.05, 2.60). Moreover, no significant differences were found in **very preterm birth** (non-Aboriginal RRR=1.48, 95%CI 0.92, 2.37; Aboriginal RRR=1.13, 95%CI 0.53, 2.39), **high birth weight** (non-Aboriginal RRR=0.97, 95%CI 0.79, 1.19; Aboriginal RRR=0.63, 95%CI 0.41, 0.96), **fetal distress** (non-Aboriginal RRR=1.15, 95%CI 0.95, 1.39; Aboriginal RRR=1.13, 95%CI 0.83, 1.53), and **>105% of optimum head circumference** (non-Aboriginal RRR=1.04, 95%CI 0.84, 1.24; Aboriginal RRR=0.67, 95%CI 0.43, 1.04). Infants of non-Aboriginal women with ID also showed significantly **low Apgar scores** (RRR=1.90, 95%CI 1.30, 2.77) when compared to non-Aboriginal women without an ID. However, no significant results in **Apgar scores** (RRR=0.83, 95%CI 0.43, 1.62) were found in infants of Aboriginal women with or without ID.
Rubenstein et al (2020)	**Pregnancy complications** Gestational hypertension Gestational diabetes **Labour variables** Induced births Caesarean delivery	N/R	Significant differences were observed in rates of **caesarean deliveries** (RR=1.25, 95%CI 1.1, 1.5) and **gestational hypertension** (RR=1.7, 95%CI 1.3, 2.3) between women with and without ID. No significant differences were found in rates of **induced births** (RR=0.96, 95%CI 0.8, 1.1), or **gestational diabetes** (RR=1.2, 95%CI 0.8, 1.7), between women with and without ID.

Mueller et al (2019)	**Pregnancy complications** Pre-eclampsia Gestational diabetes **Labour variables** Induced birth Caesarean delivery Labour augmentation **Postnatal variables** Days of hospitalisation Discharge to a place other than home Rehospitalization	**Birth and neonatal outcomes** Preterm birth • <37 weeks Birth weight • <2500g (low) Size for gestational age • <10th percentile (small) Congenital malformation Fetal distress • Relevant ICD code NICU admission **Infant outcome** • Length of hospitalisation, breastfeeding at discharge, rehospitalization within 2 years, death within 2 years	Women with ID showed significantly higher rates of **pre-eclampsia** (RR=1.88, 95%CI 1.03, 3.42), **gestational diabetes** (RR=3.39, 95%CI 1.81, 6.37), and **>3 days of hospitalisation** (RR=1.44, 95%CI 1.17, 1.78). No significant results were found in rates of **induced births** (RR=0.85, 95%CI 0.59, 1.24), **caesarean deliveries** (RR=1.23, 95%CI 0.91, 1.68), **labour augmentation** (RR=0.76, 95%CI 0.42, 1.37), **discharge to a place other than home** (RR=2.45, 95%CI 0.26, 23.42), and **rehospitalization** (RR=0.91, 95%CI 0.56, 1.47) between women with and without ID. For infants of women with ID, they showed significantly higher rates of **small for gestational age** (RR=1.78, 95%CI 1.10, 2.89), **>5 days of hospitalisation** (RR=4.47, 95%CI 2.42, 8.25), and **breastfeeding at discharge** (RR=2.68, 95%CI 1.31, 5.45). However, no significant results were found in rates of **preterm births** (RR=1.28, 95%CI 0.60, 2.76), **low birthweight** (RR=1.85, 95%CI 0.90, 3.79), **large for gestational age** (RR=0.68, 95%CI 0.28, 1.66), **fetal distress** (RR=0.85, 95%CI 0.51, 1.43), **congenital malformation** (RR=1.70, 95%CI 0.99, 2.93), **infant death** (2% in those with ID cf. 1% in those without ID), **NICU admission** (RR=1.91, 95%CI 0.71, 5.15), and **rehospitalization** (RR=0.91, 95%CI 0.56, 1.47).
Goldacre et al (2015)	**Pregnancy complications**	**Birth and neonatal outcomes**	No significant differences were observed in rates of **caesarean deliveries** (X^2=0.99, p=0.32), **pre-eclampsia** (X^2=2.81, p=0.09),

	Pre-eclampsia **Labour variables** Caesarean delivery Forceps delivery	Preterm birth • <37 weeks Birth weight Small for gestational age • <10th percentile Apgar score at 1 minute Breech presentation Stillbirth Neonatal death • <28 days after birth **Infant outcomes** Breastfeeding at discharge	and **forceps delivery** (X^2=0.02, p=0.88) when comparing between women with and without ID. For infants born to women with ID, they showed significantly higher rates of **preterm births/prolonged gestation** (X^2=12.86, p<0.01), **lower birthweight** (X^2=16.01, p=0.01), and **breastfeeding at discharge** (X=116.62, p<0.01) when compared with infants born to women without ID. However, there were no significant differences in rates of **small for gestational age** (X^2=0.49, p=0.48), **Apgar scores** (X^2=3.16, p=0.37), **breech** (X^2=0.59, p=0.75), **stillbirth** (p=0.34), and **neonatal death** (p=0.62).
Hindmarsh et al (2015)	N/R	**Birth and neonatal outcomes** Preterm birth • <37 weeks Birth weight • <2500g (low) NICU admission	Infants born to women with ID have significantly higher rates of **>2 days of hospitalisation** (OR=1.9, 95%CI 1.1, 3.3), **positive child health** (OR=5.6, 95%CI 2.6, 12.1), being **breastfed for >1 month** (OR=4.0, 95%CI 2.2, 7.4), **living with a non-smoking mother** (OR=2.9, 95%CI 1.8, 4.5), and **fine motor delay** (OR=2.0, 95%CI 1.0, 4.0) when compared to infants of women without ID. No significant differences were found in rates of **preterm births** (OR=1.4, 95%CI 0.6, 3.0), **low birthweight** (OR=1.5, 95%CI 0.7, 3.3), **NICU admission** (OR=1.6, 95%CI 0.8, 3.2), **up-to-date immunisations** (OR=1.1, 95%CI 0.3, 3.4), **rehospitalization** (OR=1.4, 95%CI 0.6, 2.5), **problems requiring a doctor** (OR=0.8,

		Problems at birth/1st week of life **Infant outcomes** • Length of hospitalisation, positive child health, immunisations up-to-date, breastfed for >1 month, gross motor delay, fine motor delay, communication delay, Carey infant temperament scale, all measured at 9 months	95%CI 0.5, 1.4), **accidents/injuries requiring a doctor/hospital** (OR=1.4, 95%CI 0.7, 2.9), **gross motor delay** (OR=0.6, 95%CI 0.2, 1.5), and the, **mood** (OR=1.5, 95%CI 0.9, 2.5), **adaptability** (OR=0.8, 95%CI 0.5, 1.3), and **regularity** (OR=0.9, 95%CI 0.6, 1.4) of the **Carey infant temperament scale**.
Höglund et al (2012a)	**Pregnancy complications** Pre-eclampsia Epidural anaesthesia Nitrous oxide No pharmacological pain relief No pain relief	**Birth and neonatal outcomes** Preterm birth • 30-36 weeks Very preterm birth • 22-29 weeks Prolonged gestation • 43-45 weeks	Results showed higher levels of **caesarean delivery** (RR=1.4, 95%CI 1.1, 1.7) and being **discharged to a place other than home** (RR=2.8, 95%CI 1.8, 4.2) in women with ID. No significant differences were noted in rates of **vacuum extraction** (RR=0.6, 95%CI 0.5, 0.9), use of **epidural anaesthesia** (RR=1.1, 95%CI 0.9, 1.2), **nitrous oxide** (RR=0.8, 95%CI 0.7, 0.9), having **no pharmacological pain relief** (RR=1.4, 95%CI 0.9, 2.0), having **no pain relief at all** (RR=0.9, 95%CI 0.3, 2.4) between women with and without ID. Results showed 1.1% of women with ID had **pre-eclampsia**, and 74.5% of women with ID experienced **spontaneous labour** compared to 81.5% in those without ID. Further details in risk ratios were not provided.

	Labour variables Spontaneous labour Caesarean delivery Vacuum extraction **Postnatal variables** Discharge to a place other than home		In infants born to women with ID, they were observed with higher rates of **preterm** (RR=1.9, 95%CI 1.4, 2.7) and **very preterm birth** (RR=3, 95%CI 1.3, 7.3) when compared to those born to women without ID. No significant differences were observed in rates of **prolonged gestation** (RR=0.9, 95%CI 0.8, 1.1).
Höglund et al (2012b)	**Labour variables** Caesarean delivery	**Birth and neonatal outcomes** Preterm birth • 30-36 weeks Very preterm birth • 22-29 weeks Prolonged gestation • 43-45 weeks Size for gestational age Apgar score at 1,5 and 10 minutes • <7 (low) Congenital malformation	Significantly higher rates of **caesarean delivery** (RR= 1.4, 95%CI 1.1, 1.7) were found in women with ID compared to those without ID. Infants born to women with ID had higher rates of **preterm birth** (RR=1.9, 95%CI 1.4, 2.7), **very preterm birth** (RR=3, 95%CI 1.3, 7.3), **small for gestational age** (RR=2.7, 95%CI 1.9, 3.9), **low Apgar score at 1 and 5 minutes** (RR=1.5, 95%CI 1.1, 2.2, RR= 2.5, 95%CI 1.4, 4.4, respectively), **stillbirth** (RR=3.9, 95%CI 1.5, 10.4), **perinatal death** (RR=4.3, 95%CI 1.9, 9.6), and **neonatal death** (RR=4.0, 95%CI 1.0, 16.0) when compared to those born to women without ID. No significant differences were found in rates of **large for gestational age** (RR=1, 95%CI 0.5, 2.1), **prolonged gestation** (RR=0.8, 95%CI 0.2, 3.4), and **congenital malformation** (RR= 1.5, 95%CI 0.9, 2.3).

		Stillbirth Perinatal death • Death from 28 weeks of gestation to one week post-natally Neonatal death • <28 days after birth	

CI, confidence interval; ID, intellectual disability; NICU, neonatal intensive care unit; N/R, not reported; OR, odds ratio; PR, prevalence ratio; RR, relative risk; UTI, urinary tract infection