Public Health England

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Health inequalities: Pregnancy and birth

Introduction

There has been increased recognition of the rights of people with learning disabilities to 'an ordinary life', including the right to be parents, with people with learning disabilities becoming more likely to develop relationships and form their own families[1]. As such, pregnancy and childbirth are important issues for women with learning disabilities.

Prevalence and risk factors

The national survey of adults with learning disabilities in England (2003/04) found that 9% of women with learning disabilities had a child[2]. A study of young people with mild or moderate learning disabilities in England found that for young women who were sexually active, those with learning disabilities were more likely to have a child than other women (for example at age 17/18, 12% versus 4%, unadjusted prevalence ratio 2.95 (95% CI 1.77-4.92))[3]. There does not appear to be any further UK data on the number of women with learning disabilities who experience pregnancy and childbirth, or UK evidence regarding risk factors for poor pregnancy and birth outcomes for women with learning disabilities.

Impact on people with learning disabilities

Women with learning disabilities experience poorer maternal wellbeing and pregnancy outcomes compared to the general population[4]. Studies from other countries have reported poorer outcomes for women with learning disabilities including:

- increased rates of pre-eclampsia
- venous thromboembolism
- pre-term birth
- delivery by caesarean section
- low birth weight
- low Apgar scores[5 6 7 8 9 10 11]

Smaller scale research in England found no difference between women with and without learning disabilities for pre-eclampsia, caesareans or Apgar scores[12]. Data

from other countries also suggest that women with learning and developmental disabilities have higher rates of postpartum hospital admissions and emergency department visits[13] but similar data relating to the UK are not available.

Perinatal mortality has been found to be higher in babies born to women with learning and developmental disabilities in the US[9], with the odds ratio for stillbirth in one US study being 2.40 (95% CI 1.70, 3.40)[11]. In one UK study combining stillbirths and infant deaths, rates per 1000 were 27.9 for babies of mothers with learning disabilities and 13.4 for other babies (borderline significant at p = 0.07), but larger UK studies are needed to determine whether stillbirth and infant death rates are higher[12].

Finally, for women with learning disabilities a safeguarding process (child protection) is much more likely to be part of their pregnancy experience[14].

Healthcare and treatment

Pregnant women with learning disabilities are less likely to seek or attend regular antenatal care[4], and struggle to understand the often text-based antenatal information communicated during pregnancy[4]. In one small scale study in the UK, no women with learning disabilities had been given easy-read pregnancy and birth information by maternity practitioners (although some had received this from other sources)[15].

Mothers with learning disabilities in the UK had less positive perceptions of their maternity care than nondisabled women, for example fewer felt that they were always spoken to in a way they could understand (66% vs. 84%)[16]. Midwives may lack training in relation to supporting women with learning disabilities, and time constraints may mean that they are unable to spend the necessary time with the women to meet their pregnancy needs[14].

A survey of supervisors of midwives from acute NHS Trusts with maternity services found that reasonable adjustments to standard antenatal information for pregnant women with learning disabilities were not common practice[17]. A quarter of NHS Trusts had a specialist/lead midwife in post for pregnant women with learning disabilities (17, 22.9%)[17], and more than half of respondents (39, 52.7%) reported that their NHS Trust had a specialist learning disability nurse in post. Less than half reported extra time being offered at the booking (29, 39.1%) or routine antenatal appointments (30, 40.5%), and less than a quarter (17, 22.9%) reported that their NHS Trust had routine antenatal written information available in accessible formats[14 17]. However, attempts have been made to develop accessible resources regarding pregnancy for people with learning disabilities and in Scotland adapted resources have been found to be helpful in supporting parents with learning disabilities to access essential information about their pregnancy and to make informed decisions about their care[18.]

Maternity services have a legal duty to make reasonable adjustments, including adapting to individual communication and learning needs, and taking the time to check that they have been fully understood[15]. The NHS Long Term Plan[19] also aims to provide midwife-led continuity of care to most women by March 2021, prioritising women in deprivation, which a Cochrane review reported to improve outcomes for the women and their baby[20].

Social determinants

Mothers and infants have more adverse health outcomes if they are from poorer and less well-educated socioeconomic backgrounds[21]. Mothers with learning disabilities in England are more likely than other mothers to be single and socio-economically deprived, to give birth at a young age, to smoke during pregnancy, and less likely to breastfeed[12].

Resources

University of Bristol Working with Parents Together Network list of resources including resources relating to pregnancy

Public Health England (2017) Screening tests for you and your baby 8 easy-read guides explaining the screening tests offered during and after pregnancy

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