Postpartum Health of Women with Intellectual and Developmental Disabilities: A Call to Action

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UNTIL THE 1970s, involuntary sterilization and institutionalization in the United States frequently prevented women with intellectual and developmental disabilities from becoming pregnant. Deinstitutionalization led to people with intellectual and developmental disabilities living in community settings in unprecedented numbers. With growing community participation and reduced stigma of disability, increasing numbers of women with intellectual and developmental disabilities are seeking to become pregnant and bear children. In fact, a recent study found comparable fertility rates between women with and without intellectual and developmental disabilities.¹

A small but growing body of literature suggests women with intellectual and developmental disabilities experience more medical complications during pregnancy and are at elevated risk for adverse maternal and birth outcomes.^{1–4} Our previous work in this area suggests that deliveries to women with intellectual and developmental disabilities are associated with increased risk of adverse birth outcomes, including preterm delivery, very low and low birth weight babies, and low Apgar scores.⁵ Compared with nondisabled women, women with intellectual and developmental disabilities are less likely to initiate prenatal care in the first trimester and less likely to breastfeed at the time of their discharge from the hospital. A recent national study found that U. S. women with intellectual and developmental disabilities were more likely to have cesarean deliveries and longer delivery-related hospital stays.⁶ In an examination of the needs of women with intellectual and developmental disabilities during pregnancy and childbirth, Potvin et al. identified the need for formal and informal social support for expectant women with intellectual and developmental disabilities.⁷ The tenuous health of expectant women with intellectual and developmental disabilities, their high rates of antenatal hospitalization, risk for pregnancy complications, and increased odds for adverse birth outcomes make it important to examine the health of these women during the postpartum period. However, to date there have been no population-based studies examining the postpartum health and healthcare experiences among women with intellectual and developmental disabilities.

In this issue of the *Journal of Women's Health*, Brown and her colleagues present the first systematic examination of the risks of postpartum medical and psychiatric hospital admissions and emergency department visits among women with intellectual and developmental disabilities compared with women without these disabilities.⁸ Using linked population-based health and social

service administrative data from Ontario, Canada, the authors found high rates of postpartum hospital admissions and emergency department visits among women with intellectual and developmental disabilities and a significantly elevated risk of hospitalizations for psychiatric reasons compared with medical reasons. Although, they acknowledge the inherent limitations in the use of administrative data, their careful analysis of hospital use in the period from delivery to 42 days post-discharge points to a need to improve postpartum follow-up efforts of women with intellectual and developmental disabilities. This type of follow-up is urgently needed, according to these findings, to prevent medical and psychiatric complications and subsequent high rates of hospital use. The authors cite the need for preventive postpartum guidelines that include a comprehensive postpartum care management plan, greater coordination between healthcare and other service providers, substantial supports between medical checkups, and more frequent, longer checkups during the postpartum period for women with intellectual and developmental disabilities.

The year following childbirth is a critical time for most mothers. It is marked by physical and emotional changes, the demands of taking care of a newborn, and an elevated risk of depression and other health problems.^{9–12} Maternal health during this time has significant and potentially lasting effects on the emotional and physical health of both mothers and their infants.¹³ Women during the postpartum period may be at risk for serious decline in their physical and mental health,⁹ and therefore are a vulnerable group requiring more preventive care postpartum.¹⁴ This period is likely more challenging for women with intellectual and developmental disabilities who have limited access to prenatal care,¹⁵ lack social and emotional support during postpartum periods,¹⁶ face significant disparities in maternal and birth outcomes,⁵ and are constrained by unique barriers to sexual and reproductive knowledge and healthcare.¹⁶ In addition to these challenges, women with intellectual and developmental disabilities are faced with significant discrimination that likely reflects societal bias against them. Approximately 30%–80% of women with intellectual and developmental disabilities have their children permanently removed by child welfare agencies.^{17–19}

Given these findings and the analysis by Brown et al.,⁸ the current American College of Obstetricians and Gynecologists (ACOG) recommendation of one postpartum visit within six weeks of delivery²⁰ is woefully inadequate for

this population of women.²¹ In the current edition of the Guidelines to Perinatal Care,²⁰ except for women with medical, obstetric, or intercurrent complications, postpartum mothers are expected to visit their physician for one postpartum visit 4–6 weeks after delivery. Critical for women with intellectual and developmental disabilities are anticipatory guidance for postpartum provided during pregnancy, including a postpartum care plan that identifies the postpartum care team for the woman and her infant with written instructions and contact information of the postpartum care team provided at the time of discharge from maternity care.²¹ Revision to the current guidelines²¹ should include appropriate emphasis of these steps for women with intellectual and developmental disabilities.

The collective research findings serve as a clarion call to change the ACOG recommendations and modify the Medicaid reimbursement policy for postpartum visits for women with intellectual and developmental disabilities. A change in Medicaid policy is imperative given that 75%–80% of deliveries among women with intellectual and developmental disabilities were to women with public insurance.⁵

These findings also underscore the need for a deeper understanding of the unmet needs, experiences, and expectations of women with intellectual and developmental disabilities during this potentially tumultuous period of their lives. Better understanding of their unmet needs and barriers to healthcare and social supports during the postpartum period would substantively inform the design and implementation of clinical practice guidelines. Recent efforts in the United States to understand and improve systems of care during the postpartum period have excluded the needs of women with disabilities, specifically women with intellectual and developmental disabilities.⁹ We hope this examination by Brown et al.⁸ and other research^{1–5,7,22} can inform the inclusion of women with intellectual and developmental disabilities in the national efforts to improve the health and wellness of new mothers and infants.

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