

# Obstetric and Gynecologic Care for Individuals with Disabilities



Kathleen E. O'Brien, MD\*, Monica Woll Rosen, MD,  
Susan Dwyer Ernst, MD

## KEYWORDS

- Intellectual disability • Physical disability • Reproductive health • Sexuality
- Education • Family planning • Disparity

## KEY POINTS

- Individuals with disabilities are less likely to receive appropriate breast and cervical cancer screening, sexual health education, and comprehensive contraceptive counseling.
- Barriers to appropriate care include provider biases and lack of training, difficulties with transportation, and inaccessible health care facilities and equipment.
- People with disabilities engage in consensual sexual activity and desire future pregnancy at rates similar to peers without disabilities.
- Individuals with disabilities enter pregnancy with unique health risks and have higher rates of severe obstetric morbidity and mortality.
- More formalized medical education and training are needed to provide patients with disabilities with optimal obstetric and gynecologic care.

## INTRODUCTION

According to the Centers for Disease Control and Prevention (CDC), more than 61 million individuals and 27% of adults in the United States are living with a disability.<sup>1</sup> The CDC defines a disability as any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions).<sup>1</sup> Disabilities can be physical, intellectual, or sensory, and individuals often have impairment in two or more of these categories.

When caring for individuals with disabilities, special considerations for support and guidance should be given to their unique needs, abilities, and barriers. The American College of Obstetricians and Gynecologists (ACOG) states, “excellent gynecologic

---

Michigan Medicine, 1500 East Medical Center Drive, Ann Arbor, MI 48104, USA

\* Corresponding author.

E-mail address: [katobr@med.umich.edu](mailto:katobr@med.umich.edu)

Obstet Gynecol Clin N Am 51 (2024) 43–56

<https://doi.org/10.1016/j.ogc.2023.10.002>

0889-8545/24/© 2023 Elsevier Inc. All rights reserved.

[obgyn.theclinics.com](http://obgyn.theclinics.com)

healthcare for women and adolescents with disabilities is comprehensive; maintains confidentiality; is an act of dignity and respect toward the patient; maximizes the patient's autonomy; avoids harm; and assesses and addresses the patient's knowledge of puberty, menstruation, sexuality, safety, and consent."<sup>2</sup> Despite these recommendations, people with disabilities experience several inequalities when receiving reproductive health care.

## HISTORY

Forced sterilization of people with intellectual disabilities (IDs) was common and became a legally protected procedure in many cultures throughout Western society in the twentieth century. This includes the United States, which has a long history of forced sterilization and legal oppression of the reproductive rights of individuals with disabilities. This practice is deeply rooted in the eugenics movement and the fear that individuals with cognitive disabilities were reproducing at a greater pace and outnumbering individuals of "normal" intelligence. One of the many goals of the eugenics movement was to promote the procreation of "fit" members of society and breeding out less desired traits. This led to the targeted sterilization of people with disabilities, immigrants, people of color, indigenous people, and people living in poverty.<sup>3</sup>

A common argument used to justify sterilization was that people with ID were not fit to parent children and that sterilization would protect them from the dangers of pregnancy.<sup>3</sup> Several laws and programs promoting segregation and sterilization were set into place in the late 1800s in the United States. Thirty-two states developed eugenics laws that legally allowed for sterilization operations to be performed on individuals with ID, with most of these procedures occurring in the 1930s to 1950s.<sup>3</sup> More than 64,000 forced sterilizations occurred in the United States under these eugenics laws, disproportionately impacting individuals with disabilities and people of color.<sup>4</sup>

In the last several decades, human rights activism has largely curbed the practice of nonconsensual sterilization. However, several states still have laws in place that can allow sterilization of individuals with disabilities if it is deemed to be in their best interest. Applications for sterilization typically require review through local courts and medical ethics committees, thereby serving as a safeguard from nonconsensual sterilization.<sup>5</sup>

In the United States, people assigned female at birth (AFAB) with both intellectual and physical disabilities continue to undergo sterilization at higher rates than people without disabilities. Individuals with cognitive disabilities have significantly higher odds of female sterilization and hysterectomy, and they undergo sterilization at significantly younger ages than people with other types of disabilities and people without disabilities.<sup>6</sup>

## BACKGROUND

Despite advances in the reproductive rights of people with disabilities, individuals with disabilities continue to experience significant stigma and barriers to reproductive health care in the United States. Numerous barriers to appropriate health care exist, including but not limited to implicit biases and discomfort among health care providers,<sup>7</sup> a lack of training in caring for individuals with disabilities,<sup>8</sup> structural barriers such as inaccessibility of medical offices and diagnostic equipment,<sup>9</sup> and difficulty with transportation to medical appointments. These barriers lead to several inequities in patient care and poor patient experiences. People with disabilities are more likely to perceive a lack of being heard, comprehensive explanation of their treatment, respect, adequate time, and shared decision-making with their physician.<sup>10</sup>

### ***Inadequate Medical Training***

---

Both in medical school and in residency, medical trainees consistently report a lack of adequate dedicated training in caring for individuals with disabilities. In regard to caring for those with disabilities, 81% of graduating medical students<sup>11</sup> reported that they had no experience or training in this area. There is significant variation in US medical school education regarding care for patients with disabilities, and demonstration of competency in caring for individuals with disabilities is not required for medical school accreditation. It was not until 2014 that the Association of American Medical Colleges directly addressed the need for competency in disability care.<sup>12</sup>

Providers in obstetrics and gynecology (OB/GYN) often do not feel trained or equipped to meet the needs of patients with physical disability and ID.<sup>8</sup> In a 2022 survey of obstetric care providers, only 12% of respondents reported having received an hour or more of training in caring for patients with ID.<sup>13</sup> A similar survey of gynecologic care providers in 2020 found that none of the respondents had ever received formal education or training on caring for individuals with disabilities who require a gynecologic examination. Those surveyed endorsed departing from screening guidelines and frustration regarding uncertainty of how to proceed with examination frequency.<sup>14</sup>

### ***Inaccessible Medical Facilities***

---

In addition to a lack of adequate training, the dearth of accessible facilities and equipment make provision of care to communities with disabilities more challenging. A 2020 survey of gynecologic care providers identified several perceived barriers to providing care for individuals with disabilities. They cited difficulty with completion of the gynecologic examination both with modifications required to the examination and transfers on and off the gynecologic examination table. They reported inadequate facilities and physical space for gynecologic examinations as a barrier to equitable care. This included narrow hallways, manual doors, small rooms, and a lack of adjustable examination tables.<sup>14</sup>

### ***Unique Gynecologic Needs***

---

Gynecologic care for people with disabilities should incorporate their unique medical, physical, and emotional needs while providing the same standard of care provided for all patients. Individuals with disabilities are at an increased risk of disability-related gynecologic conditions including catamenial seizures, medication-related hyperprolactinemia, and other endocrinopathies including insulin resistance and thyroid abnormalities. Adolescents and adults with disabilities may have difficulty at the time of menarche and subsequent tolerance of menses, leading to behavioral disruptions and distress. Nonverbal individuals with disabilities may be unable to communicate their experience of dysmenorrhea, which can lead to behavioral changes secondary to pain.

### ***Catamenial Seizures***

---

Patients with disabilities are more likely to have seizure disorders. Individuals with seizure disorders may experience cyclic seizure clusters. When the seizure exacerbations align with the menstrual cycle, this is referred to as catamenial epilepsy. Few studies have been published regarding treatment options for catamenial epilepsy, with some benefit demonstrated with continuous or cyclic progestin use, gonadotropin-releasing hormone agonists, acetazolamide, clobazam, lamotrigine, and clomiphene citrate.<sup>15</sup> If menstrual suppression is desired for treatment of catamenial epilepsy or other indications, care should be taken to choose the method of

menstrual suppression as several antiepileptic medications have interactions with estrogen-containing contraceptive agents.

### ***Inequities in Standard Screening***

Individuals with disabilities are less likely to receive routine gynecologic examinations including pelvic examinations (**Box 1**) at regular intervals, screening for sexually transmitted infections (STIs), and screening for breast and cervical cancer.

#### ***Cervical cancer screening***

Cervical cancer screening should be completed according to standard consensus guidelines. Pap testing is completed at significantly lower rates for patients with disabilities.<sup>16</sup> Individuals with physical disabilities report a lack of knowledge of cervical cancer screening and information regarding access, difficulties in accessing cancer screening providers and undergoing screening procedures, and discomfort during the screening examinations. Patients were more likely to use cervical cancer screening if there were available attendant services, wheelchair-accessible facilities, and longer appointment times.<sup>17</sup> Among people with ID, rates of cervical cancer screening are higher in those who live in residential facilities and in rural communities. Furthermore, higher rates of cervical cancer screening were also observed in those who had an OB/GYN compared with other individuals with ID.<sup>18</sup>

#### ***Breast cancer screening***

People with disabilities should be screened for breast cancer at the same recommended intervals as those for AFAB people. Routine breast cancer screening is less likely to be completed at the recommended intervals for individuals with ID compared with the general population and individuals with physical disabilities.<sup>19</sup> Barriers to routine screening include lower perceived risk for breast cancer from health care providers and difficulty with positioning for mammography.<sup>20</sup> For patients who are unable to use standard mammography equipment due to issues with physical mobility, ultrasound has been proposed as an alternative screening method.<sup>21</sup> Ultrasound is not a comparable screening examination to mammography in terms of sensitivity or specificity, but this is the best alternative available at this time. Clinical breast examinations are important and recommended for patients with disabilities who are unable to perform regular self-breast examinations or participate in breast awareness.<sup>22</sup>

#### **Box 1**

##### **Tips for the pelvic examination**

- Not needed for sole purpose of initiating contraception or menstrual suppression
- Consider urine STI screening rather than vaginal swabs
- Perform only when necessary, such as for Pap screening
- Consider transabdominal ultrasound for evaluation of abnormal uterine bleeding
- Use other positions as necessary including side lying or frog leg
- Be mindful of contractures, impaired balance, weakness, and spasticity
- Choose the speculum carefully and start with more narrow width
- For difficult examinations, consider blind Pap over one finger with a cytobrush
- For patients with intellectual disabilities, pelvic examinations may require sedation

Although the incidence of breast cancer is similar in people with ID compared with people without disabilities, breast cancer among this community tends to be diagnosed at later stages.<sup>23</sup> A 2006 study found that individuals with Social Security Disability Insurance (SSDI) and Medicare coverage had higher rates of all-cause mortality and breast cancer-specific mortality following breast cancer diagnosis. Patients with SSDI and Medicare coverage had lower rates of breast conserving surgery and were less likely to receive radiotherapy and axillary lymph node dissection.<sup>24</sup>

### **Screening for sexually transmitted infections**

Research has shown that the rates of STIs among AFAB people with disabilities are higher than in their nondisabled peers.<sup>25</sup> Increased rates of sexual assault and sexual violence among people with disabilities place individuals at an increased risk of contracting STIs. Finally, individuals with ID are less likely to receive sexual education regarding prevention and testing for STIs.<sup>26</sup> According to CDC guidelines, screening for STIs is important in patients with disabilities.

### **Contraceptive Needs**

---

Clinicians should inquire regarding the patient's needs for contraception as well as desires for future fertility. Individuals with disabilities of reproductive age engage in sexual activity at similar or higher rates compared with those without disabilities.<sup>27</sup> However, individuals with disabilities are commonly viewed as asexual or not as sexual beings,<sup>28</sup> which may lead to biases in provision of contraceptive and preconception care. Patients should receive unbiased comprehensive education regarding all available methods of contraception, including long-acting reversible contraception (LARC). In a 2013 questionnaire, AFAB people with disabilities reported a similar rate of contraceptive use at last intercourse compared with respondents without disabilities, but they were statistically more likely to use permanent sterilization as their form of contraception.<sup>29</sup> Patients with intellectual and developmental disabilities are less likely to be provided LARC and moderately effective methods of contraception. Data also suggest that they are prescribed depot medroxyprogesterone injections at higher rates than people without disabilities.<sup>30</sup>

### **Family Planning**

---

People with disabilities frequently endorse being discouraged from becoming pregnant and having children, possibly due to concerns for the individual's health and/or beliefs that people with disabilities should not become parents.<sup>31</sup> Individuals with disabilities who are of reproductive age endorse a similar rate of desire to conceive in the future as those without disabilities, at 61% and 60%, respectively.<sup>32</sup> Therefore, it is critical to assess and address the reproductive health plan for patients with disabilities.

### **Sexual and Physical Abuse**

---

People with disabilities experience higher rates of physical abuse and sexual violence, both during childhood and as adults. One meta-analysis of 17 studies including children with disabilities found a pooled prevalence of violence of 27% and 14% pooled prevalence of sexual violence. Children with disabilities in this meta-analysis were found to be three to four times more likely to be victims of violence than their peers without disabilities.<sup>33</sup> Children with disabilities are at the highest risk of sexual abuse by their caregivers and have primarily male perpetrators. Of those AFAB people with developmental disabilities, 39% to 68% will experience sexual abuse before they

reach adulthood. Approximately 65% of sexual abuse cases involve masturbation and or touching, and 31% involve actual or attempted penetration.<sup>34</sup>

People with ID experience the highest rates of sexual violence. According to the US Department of Justice Crime Statistics from 2009 to 2019, individuals with IDs have the highest rates of total violent crime, serious violent crime, and simple assault among the types of disability measured.<sup>35</sup> Individuals with ID were found to be at least seven times more likely to be sexually assaulted than individuals without disabilities. In addition to victimization through rape and sexual assault, those with ID were also more likely than their peers without disabilities to experience sexual coercion or manipulation.<sup>35</sup>

### ***Sexual Health Education***

---

Sexual education and monitoring for signs of physical or sexual abuse are within the purview of gynecologic care and should occur at routine gynecologic visits for patients with disabilities. Providers should initiate a discussion by evaluating the patient's understanding of sex and sexuality. For individuals with ID, providers should assess the patient's capacity to provide consent to sexual activity. If developmentally appropriate, a confidential interview should be completed with the patient, and the limits of confidentiality should be discussed. Sexual education should include simple but accurate terms for anatomy, sex and sexual development, sexuality, gender identity, consent, healthy expectations in romantic relationships, and sexual abuse.<sup>36</sup> For patients who are unable to provide consent to intimate contact and are at risk of sexual assault, patients and/or their families should be provided with strategies such as "NO-GO-TELL." Patients are taught to say "no" at attempted sexual contact, "go" and remove themselves from the situation, and "tell" a trusted adult.<sup>37</sup>

### ***Menstrual Suppression***

---

Individuals with disabilities often seek care from a gynecologist due to a desire to initiate menstrual suppression. This may be initiated by the patient or by parents or caregivers. When initiated by the patient, they should be treated like any other adolescent or adult who comes to the clinic requesting menstrual suppression. Providers should inquire about how menstrual periods affect the patient's life, including independence with toileting, menstrual hygiene, and impact on daily activities (**Table 1**). The patient should be questioned in private regarding the need for contraception. If the patient is currently sexually active, the provider should assess whether the relationship is consensual. Patients should be screened for high-risk behaviors at this time and offered appropriate STI screening if indicated.

When initiated by the patient's parent or caregiver, the provider should evaluate their motivation for requesting menstrual suppression. They should discuss whether menstrual periods are problematic for the patient or caregiver, and if behavioral changes and distress occur at the time of menses. The provider should question whether the parent or caregiver has a concern for underlying sexual abuse or risk of unwanted pregnancy. The patient's safety in their home and school environments should be assessed.

For adolescents with developmental disabilities, parents may seek out the initiation of menstrual suppression before the onset of menarche. Medication for menstrual suppression should not be initiated before menarche. This could expose the patient to several years of hormonal medication that are not required as menses have not yet begun. The patient should be allowed to undergo typical pubertal development without the use of exogenous hormones. Once menarche occurs, the provider should assess whether hormonal menstrual suppression is indicated at that time.

<b>Method</b>	<b>Pros</b>	<b>Cons</b>
Combined oral contraceptive pills	Higher rates of amenorrhea compared with progesterone only pills May use extended cycling or continuously	Increased risk of VTE Interacts with some antiepileptic medications Requires daily administration
Contraceptive patch	Weekly administration	May cause sensory issues Increased risk of VTE Interacts with some antiepileptic medications Continuous use is off-label
Contraceptive ring	Monthly administration	Interacts with some antiepileptic medications Increased risk of VTE
Progesterone-only pills	Less impact on VTE risk Fewer interactions with antiepileptic medications	Higher rates of breakthrough bleeding Bone mineral density loss with prolonged use Requires daily administration
Depot medroxyprogesterone	Administration every 12 wk	Weight gain Bone mineral density loss with prolonged use Longer duration of side effects
Etonogestrel implant	Administration every 3–5 y Superior contraceptive efficacy Less impact on VTE risk	May require sedation for placement Higher rates of breakthrough bleeding
Levonorgestrel IUD	Administration every 3–8 y Superior contraceptive efficacy Less impact on VTE risk	May require sedation for placement Several months of breakthrough bleeding following insertion
Endometrial Ablation	Variable amenorrhea rate	Legal and ethical implications Lower efficacy in menstrual suppression in younger adults
Hysterectomy	Complete amenorrhea	Legal and ethical implications

### **Combined hormonal contraceptives**

Combined hormonal contraceptive pills, transdermal patches, and vaginal rings may be offered for menstrual suppression in the absence of medical contraindications. This may be used in a continuous fashion or with extended cycling to limit the number of periods experienced per year. With the use of a continuous method of combined hormonal contraceptives, complete amenorrhea is achieved in 66% to 88% of patients with 1 year of use.<sup>38</sup> Combined hormonal contraceptive methods may be used to treat dysmenorrhea or cyclic symptoms such as mood changes, worsening seizure activity, or migraines. Transdermal patches may be offered in a continuous



fashion as well, though this is an off-label use and may be associated with increased odds of developing venous thromboembolism (VTE). The contraceptive ring may be offered if appropriate, though application of an intravaginal ring is often not possible or practical due to mobility limitations and the need for involvement of caregivers for administration. The most common side effect of combined hormonal contraceptives is breakthrough bleeding, particularly if being used continuously or in extended cycling. This may be treated with a 4-day hormone-free interval if breakthrough bleeding is heavy or persists longer than 48 hours.

Combined hormonal contraceptives do confer an increased risk of VTE, which may be increased at baseline for individuals who use wheelchairs or otherwise have limited mobility. The risk of VTE should be taken into consideration in the setting of additional risk factors including obesity and family history of VTE. Compared with patients who do not have multiple sclerosis (MS), patients with MS have an approximately threefold increased risk of deep vein thrombosis or VTE.<sup>39</sup>

### **PROGESTERONE-ONLY PILLS**

Progesterone-only options of menstrual suppression may be considered, particularly in the presence of contraindications to estrogen use. Of contraceptives approved by the US Food and Drug Administration (FDA), progesterone-only pills may include norethindrone and drospirenone, as well as progestins used primarily for menstrual suppression. The norethindrone package insert suggests the possibility of complete amenorrhea in approximately 20% of patients. However, a more recent assessment of our patient data suggests a rate of amenorrhea in adolescent patients closer to 40%. Patients frequently report bothersome breakthrough bleeding with the use of low-dose norethindrone.<sup>40</sup> Other progestins used for menstrual suppression may include norethindrone acetate or oral medroxyprogesterone. Patients should be counseled regarding possible mood side effects.

### **DEPOT MEDROXYPROGESTERONE ACETATE INJECTIONS**

Depot medroxyprogesterone acetate is an intramuscular injection that is typically given every 12 weeks but may be given in closer intervals for menstrual suppression and treatment of abnormal uterine bleeding. It is associated with a 60% to 70% rate of amenorrhea with regular use.<sup>41</sup> Prolonged use may cause lower bone mineral density, which may be cause for concern in patients with limited weight-bearing and mobility concerns. It may also result in mood side effects. If this is a major concern, oral medroxyprogesterone may be used first on a trial basis before administration of depot medroxyprogesterone acetate injection due to its long-acting nature.

### **ETONOGESTREL IMPLANTS**

The etonogestrel implant is a superior option particularly in patients who also require reliable contraception. The implant is FDA-approved for 3 years of use, but may provide contraceptive benefit for up to 5 years in selected populations.<sup>42</sup> It is associated with amenorrhea rates of 11% to 22%, but can be associated with significant unscheduled and breakthrough bleeding. As the etonogestrel implant requires a minor procedure for placement, sedation may be required for placement in some patients with ID.

### ***Intrauterine Devices***

Levonorgestrel-containing intrauterine devices (IUDs) are another excellent option for patients desiring both amenorrhea and reliable contraception. As the 52-mg



levonorgestrel-containing IUD is associated with the highest rates of amenorrhea, this is typically recommended as first line if the patient is considering an IUD for menstrual suppression. It is now FDA-approved for 8 years of use. Placement under intravenous (IV) sedation or general anesthesia may be considered for patients who would not tolerate placement in office.

### ***Surgical Management***

---

Patients with disabilities should be offered endometrial ablation for the same clinical indications as their peers without disabilities. Endometrial ablation is not recommended by ACOG for adolescents with disabilities for purposes of menstrual suppression or hygiene.<sup>2</sup> An endometrial ablation consists of a minor surgical procedure that causes destruction of the endometrial lining with the purpose of eliminating or lightening menses. This results in achievement of amenorrhea and approximately 25% to 40% of patients. This should only be considered for patients who have no desire for future fertility, as future pregnancy is contraindicated following an endometrial ablation due to the increased risk of abnormal placentation.

Hysterectomy is frequently requested by both individuals with disabilities and their parents and caregivers. Caregivers may question the utility of keeping the patient's uterus in situ if they would not be able to parent children and may experience difficulties secondary to menses. Hysterectomy should be completed only for medical indications and should not be performed solely for the purpose of sterilization or menstrual suppression.<sup>2</sup> A hysterectomy is a sterilization procedure, and the legal consent process must follow sterilization laws which vary between states. This typically involves court approval and possible involvement of an ethics committee if the patient is unable to provide their own consent due to ID. Although a hysterectomy would achieve complete amenorrhea and pregnancy prevention, it represents a major surgery that has a 4% to 10% rate of major complications depending on the route of hysterectomy.<sup>43</sup> In addition, a hysterectomy would not include a bilateral oophorectomy unless medically indicated, and thus, cyclical mood disturbances and behavioral changes would likely persist as the patient would continue to experience fluctuations in estrogen and progesterone.

### ***Obstetric Care***

---

#### ***Preconception counseling***

People with disabilities are more likely to report fair or poor health compared with their peers. They have higher rates of diabetes, obesity, mental distress, asthma, and lack of emotional support compared with their nondisabled counterparts. They are less likely to receive routine dental care or health maintenance examinations.<sup>44</sup> Individuals with disabilities who desire pregnancy, therefore, should be provided with preconception counseling before conceiving as they may have risk factors that are associated with adverse pregnancy outcomes.

Unique factors must be considered when providing preconception counseling to people with disabilities. Medical comorbidities should be optimized before conception. Patients should be counseled regarding the natural history of medical comorbidities in pregnancy, including medical conditions that could improve or worsen while pregnant. Care should be taken to discuss possible difficulty in differentiating between pregnancy-related symptoms and problems arising from the patient's specific disability. Medication lists should be reviewed carefully to minimize teratogenic medication exposures to the fetus. Some disabilities are associated with established or increased risk of heritable genetic conditions, and thus genetic counseling referrals should be placed when indicated.<sup>45</sup>

Preconception care is associated with improved pregnancy outcomes. A team approach is recommended when caring for a pregnant patient with a disability, including the patient's primary physician, an obstetrician, anesthesiologist, neurologist, physiatrist, and other outside health professionals including occupational and physical therapists (**Box 2**).<sup>46</sup> Evidence suggests that many pregnant people with disabilities encountered negative attitudes toward their pregnancies and report difficulty receiving comprehensive prenatal care.<sup>47</sup> Before conception, patients should be provided with information regarding health care providers and health services to facilitate appropriate prenatal and intrapartum care. Providers should assist patients with identifying potential needs and challenges during the antepartum, intrapartum, and postpartum periods.

### ***Unique Peripartum Needs***

A qualitative study including interviews of 25 individuals with physical disabilities identified several unmet needs during and around the time of pregnancy. The three main themes identified from the interviews included a lack of clinician knowledge and poor clinician attitudes, need for physical accessibility of health care facilities and equipment, and the need for information related to pregnancy and postpartum support. Their recommendations to other individuals with physical disabilities considering becoming pregnant included finding a clinician one trusts, seeking peer support, self-advocating, and preparing for the baby.<sup>48</sup>

### ***Pregnancy Outcomes***

A 2021 study from the National Institutes of Health found that individuals with disabilities are at higher risk of severe maternal morbidity and mortality. This includes higher rates of gestational diabetes, premature rupture of membranes, preterm premature rupture of membranes, placenta previa, postpartum fever, severe preeclampsia and eclampsia, and postpartum hemorrhage. Individuals with disabilities were at a sixfold increased risk of thromboembolic events and fourfold increased risk of cardiovascular events. People with disabilities also experienced more interventions at the time of birth including oxytocin augmentation, operative vaginal delivery, and cesarean birth. Cesarean deliveries were less likely to be performed for true medical indications. These adverse outcomes and increased risk of intervention were present in all categories of disability including physical, intellectual, and sensory.<sup>49</sup>

In a 2015 study of people with disabilities in Rhode Island who had recently given birth, several disparities were identified in pregnancy complications and birth outcomes. They were more likely to report stressful life events and medical complications during their most recent pregnancy, less likely to receive prenatal care in the first trimester, and more likely to have preterm births and low birth weight babies.<sup>50</sup>

#### **Box 2**

##### **Approach to care for individuals with disabilities**

- Speak directly to your patient with a normal adult tone
- Ask how your patient communicates best
- Assume and assess patient competence
- Treat assistive devices as personal space and ask before assisting
- Assess patient's physical abilities, cognitive level, and independence with activities of daily living
- Minimize sensory stimulation within the clinic

### ***Strategies to Improve Outcomes***

---

Several strategies may be considered to improve obstetric outcomes and patient experiences during pregnancy and birth. Dedicated education to the care of individuals with disabilities should be implemented in all medical school curricula, including dedicated courses or modules and the use of standardized patients with intellectual and physical disabilities. Quality improvement efforts should directly include the input of individuals with disabilities to address their perceived needs and feedback regarding their obstetric care. Obstetric providers should collaborate and communicate with the pregnant patient's other medical providers to safely tailor care during pregnancy. Trainings on implicit bias may help practitioners to recognize and correct negative attitudes toward individuals with disabilities. When developing or remodeling clinical spaces in offices and in birth centers, rooms should be tailored to promote accessibility for individuals with physical disabilities. Although these strategies will not eliminate systemic inequities faced by individuals with disabilities, they may serve to close the gap in quality of care experienced during pregnancy and childbirth.

### **SUMMARY**

In summary, people with disabilities deserve respectful and equitable OB/GYN care that lives up to the standard of care recommended for all patients. Barriers to appropriate reproductive health care include provider biases and discomfort, lack of medical education in caring for patients with disabilities, difficulties with transportation, and inaccessible health care facilities and equipment. Individuals with disabilities engage in consensual sexual activity and desire future pregnancy at rates similar to people without disabilities. They experience physical violence and sexual abuse at higher rates. They enter pregnancy with unique health risks and have higher rates of severe maternal morbidity and mortality. More formalized medical education and training are needed to provide patients with disabilities with optimal care that incorporates their unique health risks, desires for family planning, and obstetric needs.

### **CLINICS CARE POINTS**

- Patients with disabilities should be screened for cervical cancer, breast cancer, and sexually transmitted infections at the same recommended intervals as those for all people.
- Comprehensive contraceptive counseling should be provided to all people with disabilities, as they engage in consensual sexual activity at rates similar to or higher than their nondisabled peers. Individuals with disabilities continue to undergo sterilization procedures at higher rates, and hysterectomies should only be offered for the typical medical indications.
- People with intellectual disabilities are at particularly increased risk of physical abuse and sexual violence, and obstetrician and gynecologists should assess for safety concerns at routine visits.
- When choosing a method of menstrual suppression, consideration should be paid to the individual's personal risks, including increased risk of venous thromboembolism with immobilization and interactions with antiepileptic medications.
- Owing to the increased risks of maternal mortality and all severe maternal morbidities during pregnancy and postpartum, individuals with disabilities should receive tailored preconception counseling and comprehensive obstetric care.

## DISCLOSURES

The authors have no financial disclosures.

## REFERENCES

1. CDC. Disability and health overview. Centers for Disease Control and Prevention. Published September 16, 2020. Accessed June 14, 2023. <https://www.cdc.gov/ncbddd/disabilityandhealth/disability.html>.
2. American College of Obstetricians and Gynecologists' Committee on Adolescent Health Care. Committee opinion no. 668: Menstrual manipulation for adolescents with physical and developmental disabilities. *Obstet Gynecol* 2016;128(2):e20–5.
3. Grekul J, Krahn A, Odynak D. Sterilizing the “feeble-minded”: Eugenics in Alberta, Canada, 1929–1972. *J Hist Sociol* 2004;17(4):358–84.
4. Lombardo P. Eugenic sterilization laws. Published online May 10, 2007. Accessed July 30, 2023. <https://repository.library.georgetown.edu/handle/10822/524974>.
5. Rowlands S, Amy JJ. Sterilization of those with intellectual disability: Evolution from non-consensual interventions to strict safeguards. *J Intellect Disabil* 2019;23(2):233–49.
6. Li H, Mitra M, Wu JP, et al. Female Sterilization and Cognitive Disability in the United States, 2011–2015. *Obstet Gynecol* 2018;132(3):559.
7. Smeltzer SC, Mitra M, Long-Bellil L, et al. Obstetric clinicians' experiences and educational preparation for caring for pregnant women with physical disabilities: A qualitative study. *Disabil Health J* 2018;11(1):8–13.
8. Taouk LH, Fialkow MF, Schulkin JA. Provision of Reproductive Healthcare to Women with Disabilities: A Survey of Obstetrician–Gynecologists' Training, Practices, and Perceived Barriers. *Health Equity* 2018;2(1):207–15.
9. Nosek MA, Young ME, Rintala DH, et al. Barriers to Reproductive Health Maintenance Among Women with Physical Disabilities. *J Womens Health* 1995;4(5):505–18.
10. Smith DL. Disparities in patient-physician communication for persons with a disability from the 2006 Medical Expenditure Panel Survey (MEPS). *Disabil Health J* 2009;2(4):206–15.
11. Holder M, Waldman HB, Hood H. Preparing health professionals to provide care to individuals with disabilities. *Int J Oral Sci* 2009;1(2):66–71.
12. Santoro JD, Yedla M, Lazzareschi DV, et al. Disability in US medical education: Disparities, programmes and future directions. *Health Educ J* 2017;76(6):753–9.
13. Amir N, Smith LD, Valentine AM, et al. Clinician perspectives on the need for training on caring for pregnant women with intellectual and developmental disabilities. *Disabil Health J* 2022;15(2):101262.
14. Sonalkar S, Chavez V, McClusky J, et al. Gynecologic Care for Women With Physical Disabilities: A Qualitative Study of Patients and Providers. *Wom Health Issues* 2020;30(2):136–41.
15. Herzog AG. Catamenial epilepsy: definition, prevalence pathophysiology and treatment. *Seizure* 2008;17(2):151–9.
16. Iezzoni LI, Kurtz SG, Rao SR. Trends in Pap Testing Over Time for Women With and Without Chronic Disability. *Am J Prev Med* 2016;50(2):210–9.
17. Chan DNS, Law BMH, So WKW, et al. Factors associated with cervical cancer screening utilisation by people with physical disabilities: A systematic review. *Health Pol* 2022;126(10):1039–50.

18. Parish SL, Swaine JG, Son E, et al. Determinants of cervical cancer screening among women with intellectual disabilities: evidence from medical records. *Publ Health Rep* 2013;128(6):519–26.
19. Iezzoni LI, Kurtz SG, Rao SR. Trends in mammography over time for women with and without chronic disability. *J Womens Health* 2015;24(7):593–601.
20. Shin DW, Yu J, Cho J, et al. Breast cancer screening disparities between women with and without disabilities: A national database study in South Korea. *Cancer* 2020;126(7):1522–9.
21. Breastcancer.org. Detection rates similar to mammograms, ultrasound may be option if mammography isn't available. Breastcancer.org. Published January 9, 2016. Accessed July 30, 2023. <https://www.breastcancer.org/research-news/ultrasound-may-be-alternative-to-mammo>.
22. Wisdom JP, McGee MG, Horner-Johnson W, et al. Health Disparities Between Women With and Without Disabilities: A Review of the Research. *Soc Work Publ Health* 2010;25(3–4):368–86.
23. Batchelor NC. Breast cancer incidence and stage at diagnosis in ontarians with and without intellectual disabilities. University of Ontario Institute of Technology; 2017. <https://api.core.ac.uk/oai/oai:ir.library.dc-uoit.ca:10155/799>.
24. McCarthy EP, Ngo LH, Roetzheim RG, et al. Disparities in breast cancer treatment and survival for women with disabilities. *Ann Intern Med* 2006;145(9):637–45.
25. Brennand EA, Santinele Martino A. Disability is associated with sexually transmitted infection: Severity and female sex are important risk factors. *Can J Hum Sex* 2022;31(1):91–102.
26. Tilley E, Walmsley J, Earle S, et al. “The silence is roaring”: sterilization, reproductive rights and women with intellectual disabilities. *Disabil Soc* 2012;27(3):413–26.
27. 2015 Oregon Healthy Teen Data.; 2016.
28. Esmail S, Darry K, Walter A, et al. Attitudes and perceptions towards disability and sexuality. *Disabil Rehabil* 2010;32(14):1148–55.
29. Haynes RM, Boulet SL, Fox MH, et al. Contraceptive use at last intercourse among reproductive-aged women with disabilities: an analysis of population-based data from seven states. *Contraception* 2018;97(6):538–45.
30. Wu J, Zhang J, Mitra M, et al. Provision of Moderately and Highly Effective Reversible Contraception to Insured Women With Intellectual and Developmental Disabilities. *Obstet Gynecol* 2018;132(3):565–74.
31. Personal experiences of pregnancy and fertility in individuals with spinal cord injury. *Sex Disabil* 2014;32(1):65–74.
32. Bloom TL, Mosher W, Alhusen J, et al. Fertility Desires and Intentions Among U.S. Women by Disability Status: Findings from the 2011–2013 National Survey of Family Growth. *Matern Child Health J* 2017;21(8):1606–15.
33. Jones L, Bellis MA, Wood S, et al. Prevalence and risk of violence against children with disabilities: a systematic review and meta-analysis of observational studies. *Lancet* 2012;380(9845):899–907.
34. Bowman RA, Scotti JR, Morris TL. Sexual abuse prevention: a training program for developmental disabilities service providers. *J Child Sex Abuse* 2010;19(2):119–27.
35. Harrell E. Crime against persons with disabilities, 2009–2019 – statistical tables. Published online 2021. Accessed June 30, 2023. <https://calio.dspacedirect.org/handle/11212/5269>.

36. Breuner CC, Mattson G. Committee on adolescence, committee on psychosocial aspects of child and family health. sexuality education for children and adolescents. *Pediatrics* 2016;138(2). <https://doi.org/10.1542/peds.2016-1348>.
37. Holland-Hall C, Quint EH. Sexuality and Disability in Adolescents. *Pediatr Clin North Am* 2017;64(2):435–49.
38. Wright KP, Johnson JV. Evaluation of extended and continuous use oral contraceptives. *Therapeut Clin Risk Manag* 2008;4(5):905–11.
39. Houtchens MK, Zapata LB, Curtis KM, et al. Contraception for women with multiple sclerosis: Guidance for healthcare providers. *Mult Scler* 2017;23(6):757–64.
40. Fei YF, Ernst SD, Dendrinios ML, et al. Preparing for Puberty in Girls With Special Needs: A Cohort Study of Caregiver Concerns and Patient Outcomes. *J Pediatr Adolesc Gynecol* 2021;34(4):471–6.
41. Dural Ö, Taş İS, Akhan SE. Management of Menstrual and Gynecologic Concerns in Girls with Special Needs. *J Clin Res Pediatr Endocrinol* 2020;12(Suppl 1):41–5.
42. Ali M, Akin A, Bahamondes L, et al. Extended use up to 5 years of the etonogestrel-releasing subdermal contraceptive implant: comparison to levonorgestrel-releasing subdermal implant. *Hum Reprod* 2016;31(11):2491–8.
43. Settnes A, Moeller C, Topsoe MF, et al. Complications after benign hysterectomy, according to procedure: a population-based prospective cohort study from the Danish hysterectomy database, 2004-2015. *BJOG* 2020;127(10):1269–79.
44. Mitra M, Clements KM, Zhang J, et al. Disparities in Adverse Preconception Risk Factors Between Women with and Without Disabilities. *Matern Child Health J* 2016;20(3):507–15.
45. Ruhl C, Moran B. The clinical content of preconception care: preconception care for special populations. *Am J Obstet Gynecol* 2008;199(6 Suppl 2):S384–8.
46. Thierry JM. The importance of preconception care for women with disabilities. *Matern Child Health J* 2006;10(5 Suppl):S175–6.
47. Rogers J. *ReadHowYouWant.com, Demos Health*. 2010.
48. Mitra M, Long-Bellil LM, Iezzoni LI, et al. Pregnancy among women with physical disabilities: Unmet needs and recommendations on navigating pregnancy. *Disabil Health J* 2016;9(3):457–63.
49. Gleason JL, Grewal J, Chen Z, et al. Risk of Adverse Maternal Outcomes in Pregnant Women With Disabilities. *JAMA Netw Open* 2021;4(12):e2138414.
50. Mitra M, Clements KM, Zhang J, et al. Maternal Characteristics, Pregnancy Complications, and Adverse Birth Outcomes Among Women With Disabilities. *Med Care* 2015;53(12):1027–32.