Women With Disabilities Need Gynecologists Too

Grace Lau, MD

Department of Obstetrics and Gynecology

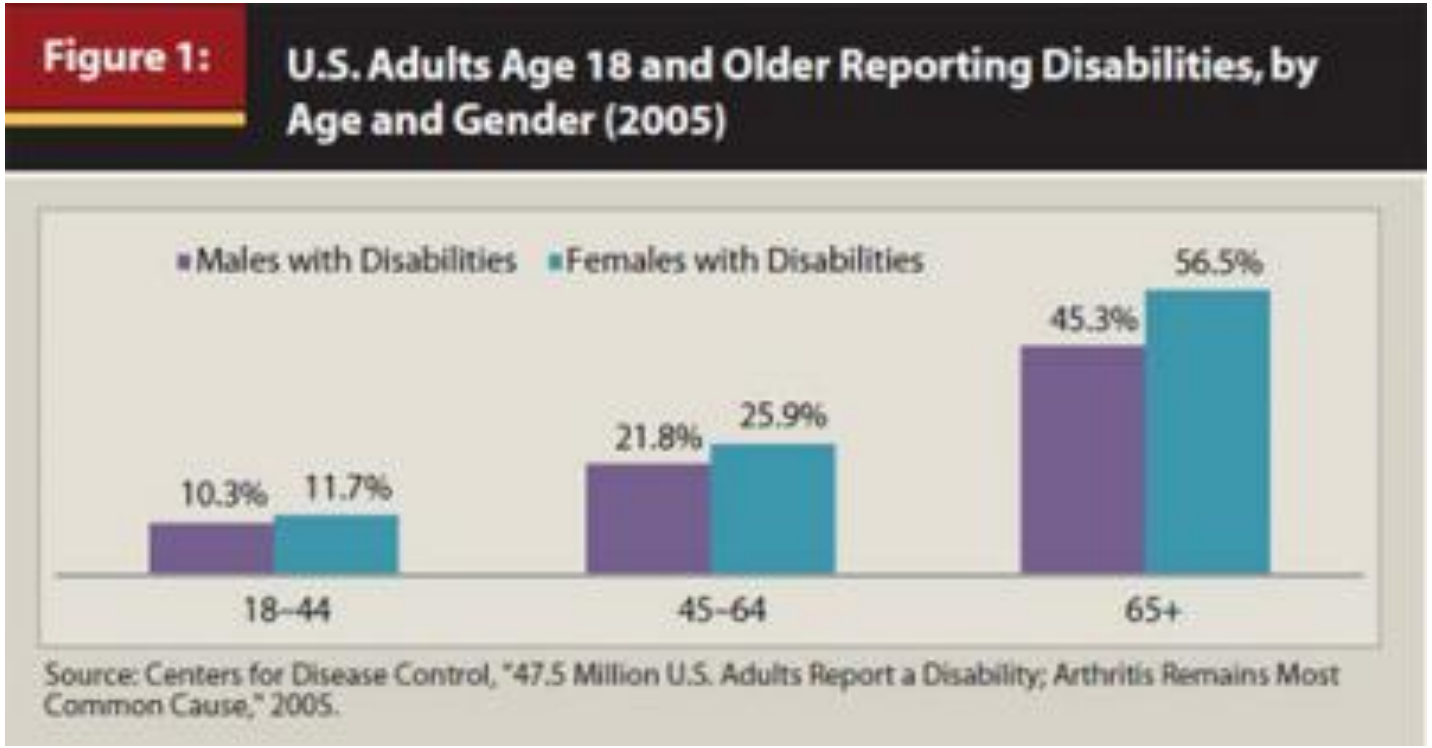
New York University School of Medicine

Patient

JS is a 42 yo woman with cerebral palsy, wheelchair dependent who presents to office for her first gynecologic exam. Her primary care physician suggested it years ago, but she hasn't found an office to accommodate her. She has never had a pap smear. She has been sexually active in the past, but has never used contraception. Her periods are heavy and crampy, and she has iron deficiency anemia.

Women with disabilities

- About 36 million women in the U.S. have disabilities
- The prevalence of any disability is higher in women compared with men
- About 44% of those aged 65 years or older are living with a disability.

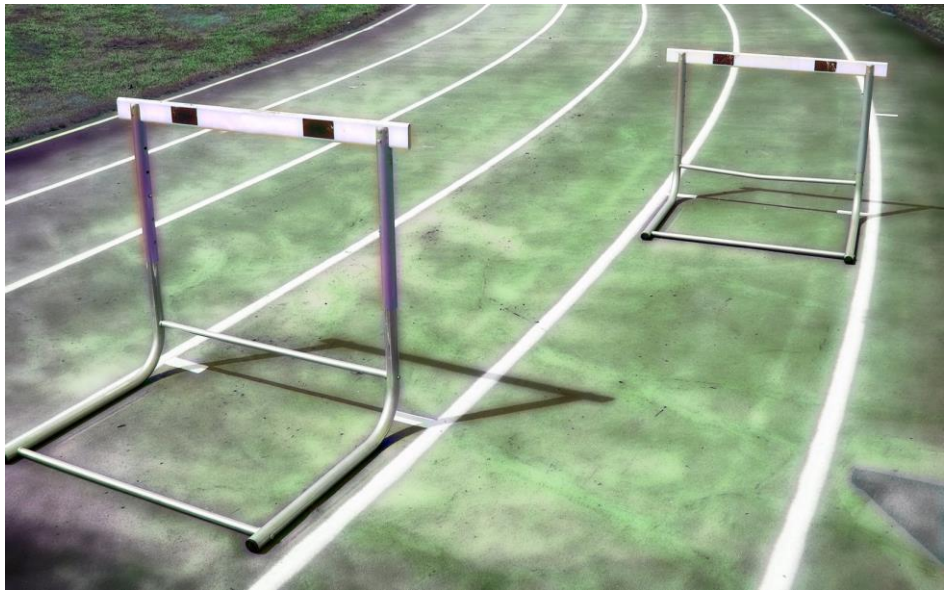


General Approach

- According to the American College of Obstetricians and Gynecologists (ACOG), “excellent gynecologic health care 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.”

Barriers to gynecologic care

- Barriers to care stem from a number of factors such as lack of knowledge and skills among providers, inadequate office settings and the amount of time providers are able to spend with patients with disabilities.
- Women with disabilities require the same primary and preventive reproductive health care that women without disabilities require.
- Better understanding of the gynecologic needs of women with disabilities is imperative.



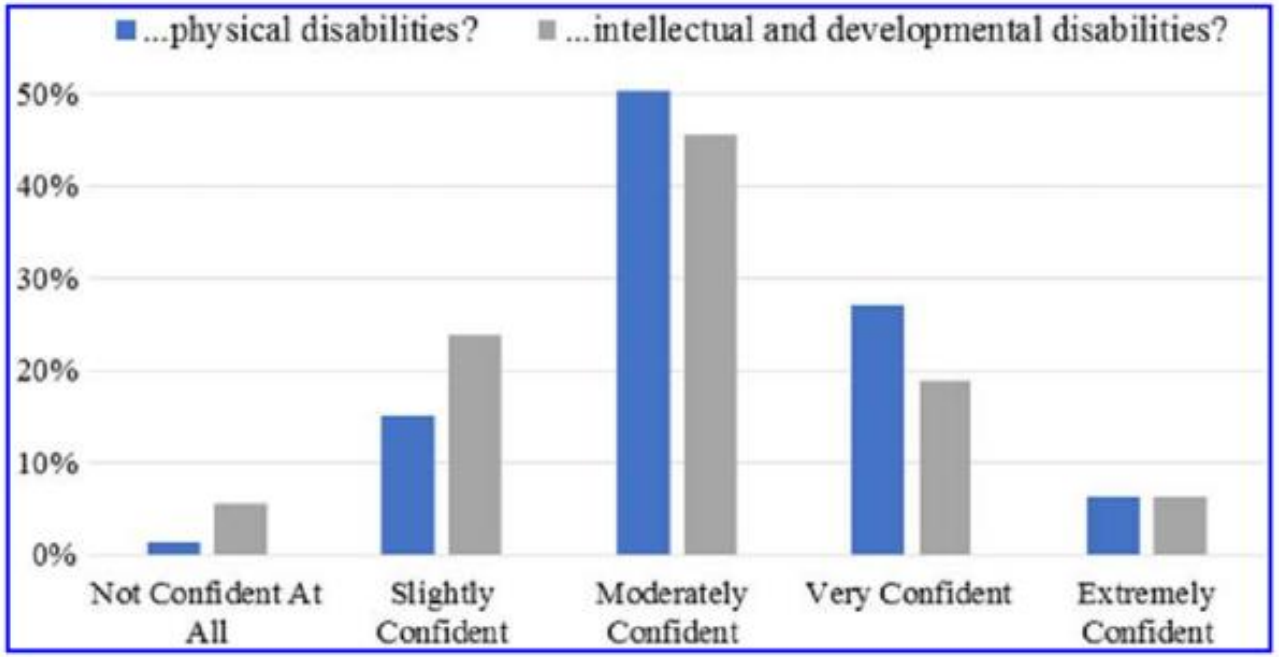
Environmental Access Barriers

- Physical accessibility
- Environmental inaccessibility
- Hospitals can also pose accessibility challenges.
- Other environmental barriers in clinics include
  - Inappropriate examining instruments
  - Inaccessible or inadequately padded stirrups
  - In one study, only 39% of GYN care providers an exam table that could adjust, and only 2% had a platform or sitting scale

Schopp *et al*. Journal of Midwifery and Women's Health. 2010

Informational Barriers

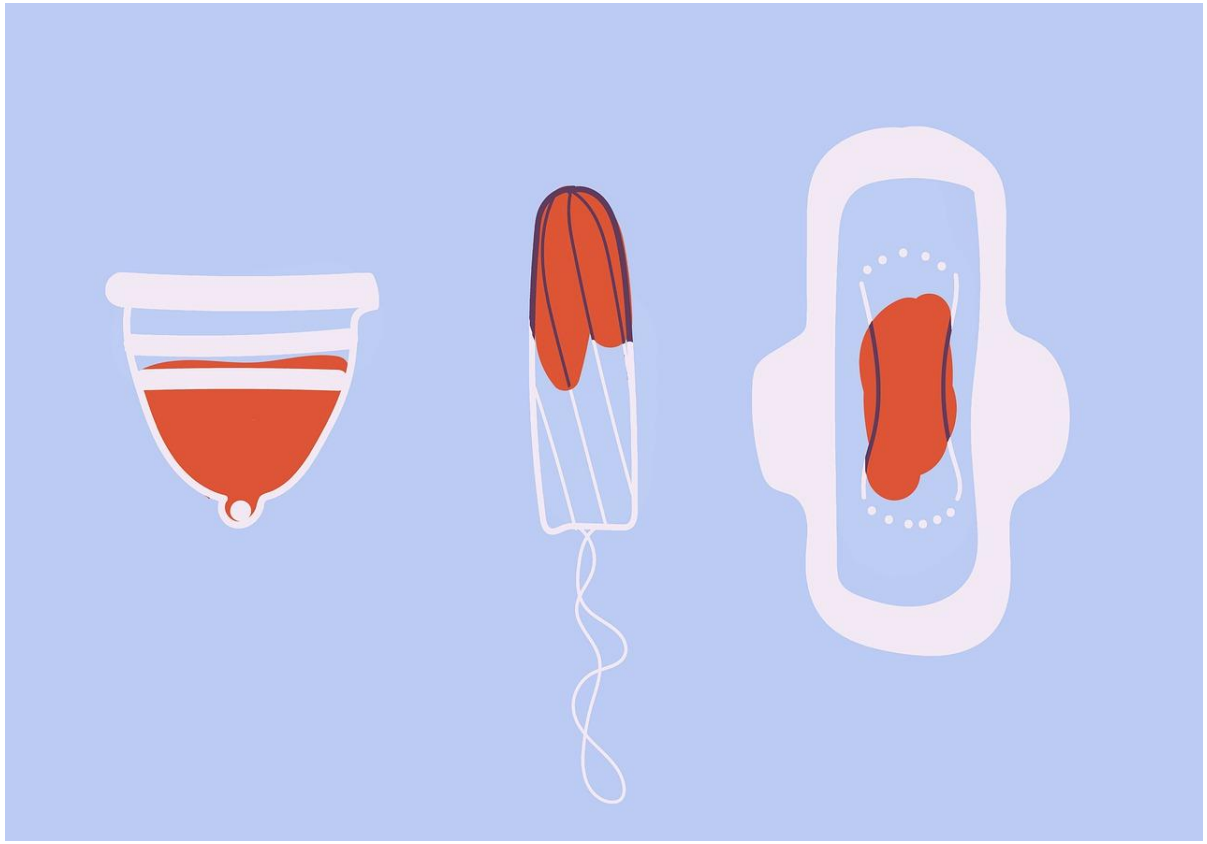
- Lack of information or training on the provision of health care to women with disabilities
- Women with disabilities are frequently not able to access information about their own gynecologic health care needs
- Decreased confidence in OBGYN providers in their ability to provide care:



Taouk et al. Health Equity 2018

Menstruation

- Menstruation is a monthly occurrence for 1.8 billion girls and women of reproductive age.
- Women with disabilities are often found to have more menstrual issues.
- The management of menstruation can prove difficult for some with limited physical functions.
- A 2019 review found that menstruation challenges were a source of shame for girls and women with disabilities
- Menstruating girls and women with different types of disabilities may have different needs.



UNICEF. Menstrual health and hygiene for girls and women with disabilities

Menstrual management

- Periods can affect independence and add additional concerns for life at home, schools, and residences
- Menstrual management
  - Normal to minimize hygienic issues, PMS, dysmenorrhea
  - Abnormal cycles – menorrhagia, irregular cycles, intermenstrual bleeding

Risk factors for menstrual irregularities in women with disabilities

- Medical comorbidities
  - Obesity
  - Thyroid diseases
  - Seizure disorders
  - Polycystic ovary syndrome
- Medication adverse effects
  - Medications that affect the dopaminergic system can cause high prolactin levels (risperidone, amitriptyline, methyldopa)

Initial Evaluation

- Elicit menstrual cycle parameters
  - Cycle length
  - Days of menstruation
  - Heaviness of bleeding
  - Dysmenorrhea
  - Behavioral and mood changes associated with periods
- Menstrual records are helpful
  - Also symptom calendars to determine if symptom is cyclical

Screening Tool for Identifying Women with Menorrhagia for Testing and Evaluation for Underlying Bleeding Disorders

Instructions: *Circle the appropriate response for each of the eight (8) questions below.*

1. ***How many days did your period usually last, from the time bleeding began until it completely stopped?***
   i. Less than 7 days
   ii. Greater than or equal to 7 days
   iii. Don't know

2. ***How often did you experience a sensation of "flooding" or "gushing" during your period?***
   i. Never, rarely, or some periods
   ii. Every or most periods
   iii. Don't know

3. ***During your period did you ever have bleeding where you would bleed through a tampon or napkin in 2 hours or less?***
   i. Never, rarely, or some periods
   ii. Every or most periods
   iii. Don't know

4. ***Have you ever been treated for anemia?***
   i. No
   ii. Yes
   iii. Don't know

5. ***Has anyone in your family ever been diagnosed with a bleeding disorder?***
   i. No
   ii. Yes
   iii. Don't know

6. ***Have you ever had a tooth extracted or had dental surgery?***
   i. No (If no, go to question 7)
   ii. Yes
   iii. Don't know

   a. ***Did you have a problem with bleeding after tooth extraction or dental surgery?***
      i. No
      ii. Yes
      iii. Don't know

National Center on Birth Defects and Developmental Disabilities
Division of Blood Disorders

CS252755-A

7. ***Have you ever had surgery other than dental surgery?***
   i. No (If no, go to question 8)
   ii. Yes
   iii. Don't know

   a. ***Did you have bleeding problems after surgery?***
      i. No
      ii. Yes
      iii. Don't know

8. ***Have you ever been pregnant?***
   i. No
   ii. Yes
   iii. Don't know

   a. ***Have you ever had a bleeding problem following delivery or after a miscarriage?***
      i. No
      ii. Yes
      iii. Don't know

How to Use the Screening Tool

The screening tool is considered to be positive if 1 of the following 4 criteria were met:

1. The duration of menses was greater than or equal to 7 days and the woman reported either "flooding" or bleeding through a tampon or napkin in 2 hours or less with most periods;
2. A history of treatment of anemia;
3. A family history of a diagnosed bleeding disorder; or
4. A history of excessive bleeding with tooth extraction, delivery or miscarriage, or surgery

Sources:

Philipp CS, Faiz A, Dowling NF, et al. Development of a screening tool for identifying women with menorrhagia for hemostatic evaluation. *Am J Obstet Gynecol* 2008; 163.e1-163.e8.

Philipp CS, Faiz A, Heit JA, et al. Evaluation of a screening tool for bleeding disorders in a US multisite cohort of women with menorrhagia. *Am J Obstet Gynecol* 2011; 204:209.e1-7.

Decision for menstrual management

- Based on discussion with patient and parents/guardians
- Clinical considerations (i.e. anemia) and social context (hygiene)
- Menstrual suppression does not change risk of abuse or sexually transmitted disease
- The decision to suppress menses in women with physical disabilities is cased on whether the patient believes this will help her life
- In families with a patient with severe intellectual disabilities, the issues are more complicated if there is no clear medical indication.
  - Further investigation into pt's circumstances, offer help to address the needs

Quint and O'Brien. Pediatrics. 2016

Issues

- It is difficult to guarantee complete amenorrhea
- Important to set outcome goals and length of time to achieve outcome
- The goal in menstrual manipulation should be optimal suppression
- All menses management methods have pros and cons

Treatment options

Table 1. Overview of Menstrual Management Methods for Adolescents With Special Needs ⇦

Treatment	Specific Benefits	Disability Concerns
NSAIDs	Decreases flow and pain	GI issues
Combined oral contraceptives	Can use extended or continuous regimen	If immobile: possible risk of VTE Daily reminders Interfere with certain EI-AED
Contraceptive patch	Weekly application Can use extended or continuous regimen	If immobile: possible risk of VTE Patient can remove from skin Interfere with certain EI-AED
Contraceptive ring	Monthly Can use extended or continuous regimen	If immobile: possible risk of VTE Placement by others (privacy) Interfere with certain EI-AED
Oral progestin	Decreased flow	BTB Daily reminders Interfere with certain EI-AED
Depot medroxyprogesterone acetate	Every 3 months	Weight gain in obese adolescents
Progesterone implant	Every 3 years Decreased dysmenorrhea	BTB Insertion may be challenging
LNG-IUD	Every 3–5 years	Challenging insertion, may need anesthesia Initial BTB
Surgical methods: hysterectomy	Complete amenorrhea	Legal and ethical implications Major surgery

Abbreviations: BTB, breakthrough bleeding; EI-AED, enzyme-inducing antiepileptic drugs; GI, gastrointestinal; LNG-IUD, levonorgestrel intrauterine device; NSAIDs, nonsteroidal antiinflammatory drugs; VTE, venous thromboembolism.

Modified from Quint EH. Adolescents with special needs: clinical challenges in reproductive health care. J Pediatr Adolesc Gynecol 2016;29:2–6.

OBSTETRICS & GYNECOLOGY

Committee Opinion No. 668: Menstrual Manipulation for Adolescents With Physical and Developmental Disabilities. Obstetrics & Gynecology 2016.

Progesterone Intrauterine Device

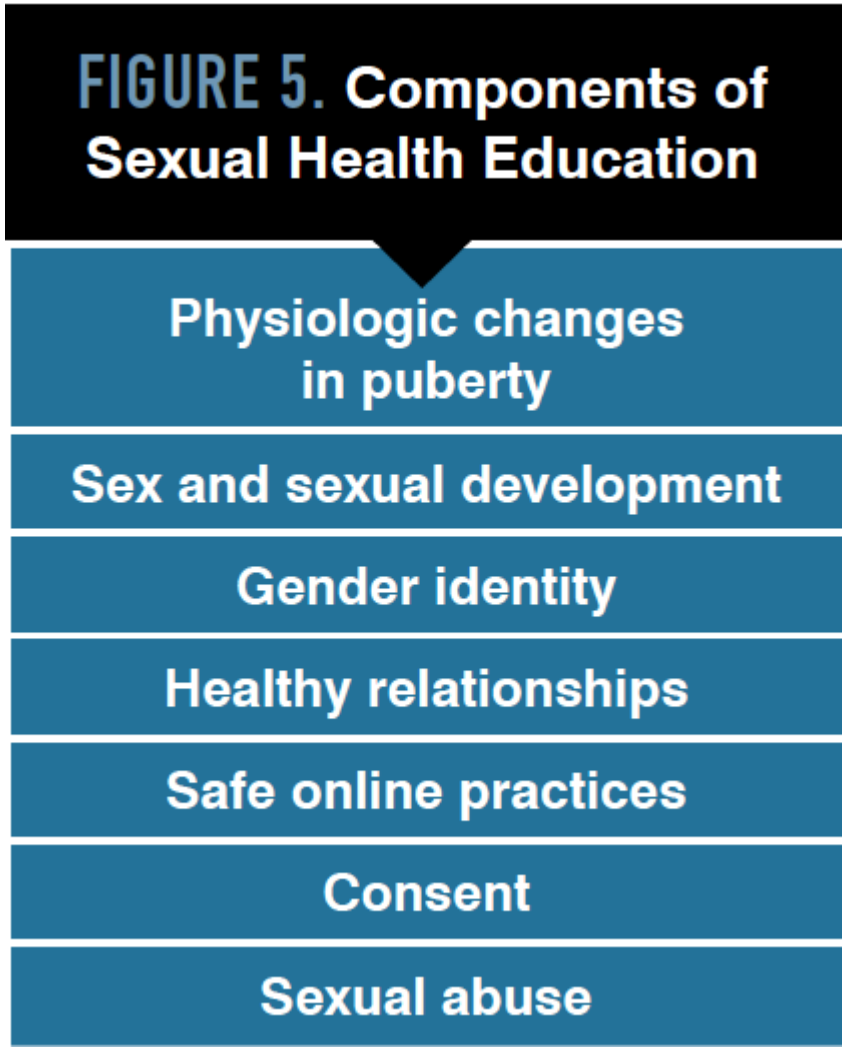
Sexual health

Sexual history

- Women with disabilities are often incorrectly considered to be asexual or uninvolved in a relationship
- Teenagers with disabilities are just as likely to be sexually active as their peers
- Have a higher incidence of sexually transmitted infections, unintended pregnancies, sexual abuse and violence compared with the general population
- Women with a disability are more likely to experience intimate partner violence including sexual and physical violence, stalking, psychological aggression, and control of reproductive or sexual health when compared to women without a disability.
- Women with disabilities at greater risk for sexual dysfunction, low libido, and desire.
- Common causes include social factors: poverty, illiteracy, lack of access to health recourse and lack of power when negotiating safer sex

Rowen, TS. The Journal of Sexual Medicine. 2013

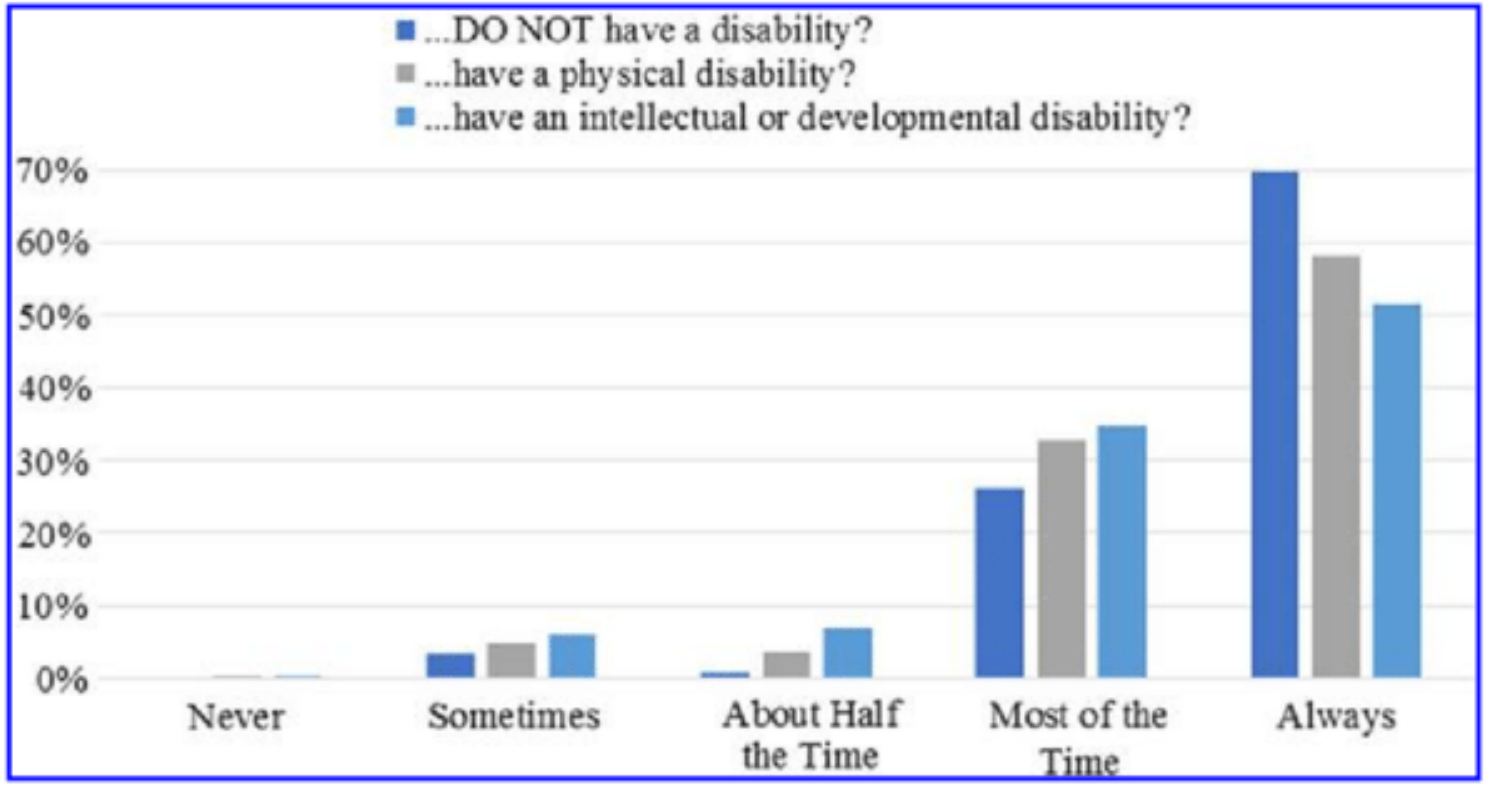
Components of sexual health education



Ernst *et al*. Gynecology. 2022

Frequency of contraception counseling

Responses to, ''in your current practice, how often do you initiate contraceptive counseling with women of reproductive age who (1) do not have a disability; (2) have a physical disability; (3) have an intellectual or developmental disability

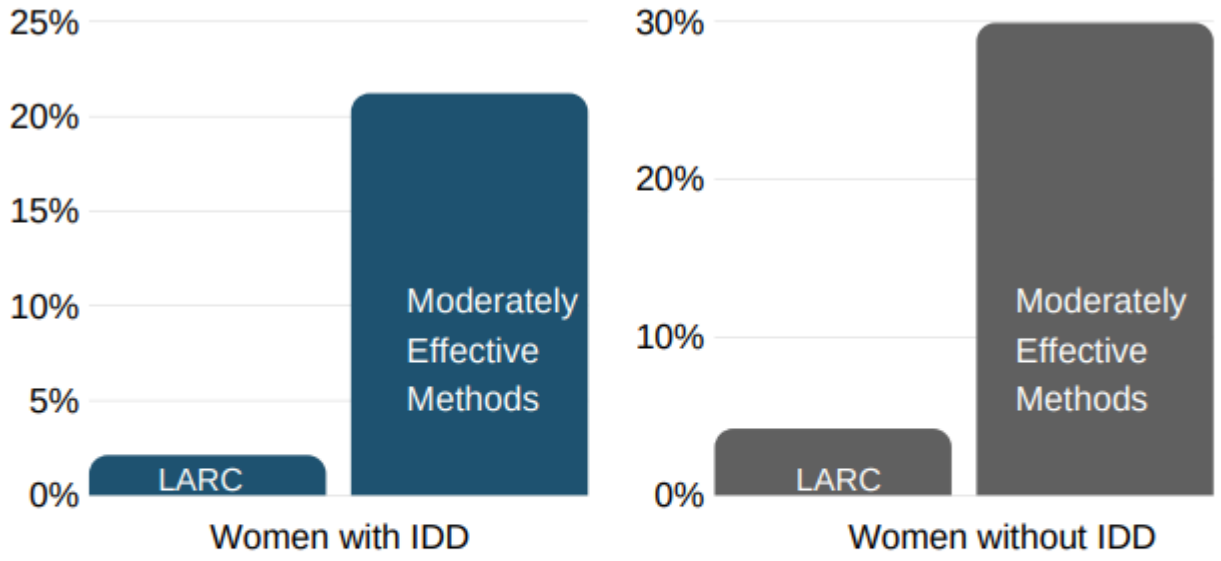


Taouk *et al*. Health Equity 2018

Access to contraception

- Long-Acting Reversible Contraceptives (LARC) and Moderately and Highly Effective Reversible Contraception

- Women with IDD are less likely to get a LARC than
- Women with IDD are less likely to get a moderately and highly effective reversible contraception than women without these disabilities.



Adapted from: Wu J., Zhang J., Mitra M., Parish S., Kavya M., Reddy G. (2018). Provision of Moderately and Highly Effective Reversible Contraception to Insured Women With Intellectual and Developmental Disabilities. Obstetrics & Gynecology. 132(3):565-574

Contraceptive counseling for patients with IDD

Patient is an 18 yo with a rare genetic syndrome and mild cognitive impairment came into gynecology clinic for first exam with her mother. The patient lives with her parents. After the patient and her mother were interviewed together, the mother left the room and a confidential interview was conducted with the patient. She reported she had a boyfriend of several months and was interested in becoming sexually active soon.

HOW WELL DOES BIRTH CONTROL WORK?

Really, really well

	The Implant (Nexplanon)	IUD (Skyla)	IUD (Mirena)	IUD (ParaGard)	Sterilization, for men and women
Works, hassle-free, for up to...	3 years	3 years	5 years	12 years	Forever

Okay

	The Pill	The Patch	The Ring	The Shot (Depo-Provera)
For it to work best, use it...	Every. Single. Day.	Every week	Every month	Every 3 months

Not so well

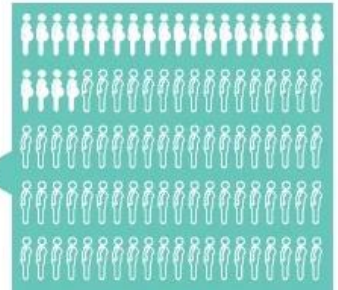
	Withdrawal	Diaphragm	Fertility Awareness	Condoms, for men and women

For each of these methods to work, you or your partner have to use it every single time you have sex.

What is your chance of getting pregnant?

Less than 1 in 100 women

6-9 in 100 women, depending on method



12-24 in 100 women, depending on method

FYI, without birth control, over 90 in 100 young women get pregnant in a year.

BEDSIDER
Bedsider.org

Bixby Center for Global Reproductive Health

Summary Chart of U.S. Medical Eligibility Criteria for Contraceptive Use

Centers for Disease Control and Prevention
National Center for Chronic Disease Prevention and Health Promotion

Condition	Sub-Condition	Cu-IUD		LNG-IUD		Implant		DMPA		POP		CHC	
		I	C	I	C	I	C	I	C	I	C	I	C
Age		Menarche to <20 yrs:2		Menarche to <20 yrs:2		Menarche to <18 yrs:1		Menarche to <18 yrs:2		Menarche to <18 yrs:1		Menarche to <40 yrs:1	
		≥20 yrs:1		≥20 yrs:1		18-45 yrs:1		18-45 yrs:1		18-45 yrs:1		≥40 yrs:2	
						>45 yrs:1		>45 yrs:2		>45 yrs:1			
Anatomical abnormalities	a) Distorted uterine cavity	4		4									
	b) Other abnormalities	2		2									
Anemias	a) Thalassemia	2		1		1		1		1		1	
	b) Sickle cell disease‡	2		1		1		1		1		2	
	c) Iron-deficiency anemia	2		1		1		1		1		1	
Benign ovarian tumors	(*including cysts*)	1		1		1		1		1		1	
Breast disease	a) Undiagnosed mass	1		2		2*		2*		2*		2*	
	b) Benign breast disease	1		1		1		1		1		1	
	c) Family history of cancer	1		1		1		1		1		1	
	d) Breast cancer‡												
	i) Current	1		4		4		4		4		4	
	ii) Past and no evidence of current disease for 5 years	1		3		3		3		3		3	
Breastfeeding	a) <21 days postpartum					2*		2*		2*		4*	
	b) 21 to <30 days postpartum												
	i) With other risk factors for VTE					2*		2*		2*		3*	
	ii) Without other risk factors for VTE					2*		2*		2*		3*	
	c) 30-42 days postpartum												
	i) With other risk factors for VTE					1*		1*		1*		3*	
	ii) Without other risk factors for VTE					1*		1*		1*		2*	
	d) >42 days postpartum					1*		1*		1*		2*	
Cervical cancer	Awaiting treatment	4	2	4	2	2		2		1		2	
Cervical ectropion		1		1		1		1		1		1	
Cervical intraepithelial neoplasia		1		2		2		2		1		2	
Cirrhosis	a) Mild (*compensated*)	1		1		1		1		1		1	
	b) Severe† (*decompensated*)	1		3		3		3		3		4	
Cystic fibrosis‡		1*		1*		1*		2*		1*		1*	
Deep venous thrombosis (DVT)/Pulmonary embolism (PE)	a) History of DVT/PE, not receiving anticoagulant therapy												
	i) Higher risk for recurrent DVT/PE	1		2		2		2		2		4	
	ii) Lower risk for recurrent DVT/PE	1		2		2		2		2		3	
	b) Acute DVT/PE	2		2		2		2		2		4	
	c) DVT/PE and established anticoagulant therapy for at least 3 months												
	i) Higher risk for recurrent DVT/PE	2		2		2		2		2		4*	
	ii) Lower risk for recurrent DVT/PE	2		2		2		2		2		3*	
	d) Family history (*first-degree relatives*)	1		1		1		1		1		2	
	e) Major surgery												
	i) With prolonged immobilization	1		2		2		2		2		4	
	ii) Without prolonged immobilization	1		1		1		1		1		2	
	f) Minor surgery without immobilization	1		1		1		1		1		1	
Depressive disorders		1*		1*		1*		1*		1*		1*	

Condition	Sub-Condition	Cu-IUD		LNG-IUD		Implant		DMPA		POP		CHC	
		I	C	I	C	I	C	I	C	I	C	I	C
Diabetes	a) History of gestational disease	1		1		1		1		1		1	
	b) Nonvascular disease												
	i) Non-insulin dependent	1		2		2		2		2		2	
	ii) Insulin dependent	1		2		2		2		2		2	
	c) Nephropathy/retinopathy/neuropathy‡	1		2		2		3		2		3/4*	
	d) Other vascular disease or diabetes of >20 years' duration‡	1		2		2		3		2		3/4*	
Dysmenorrhea	Severe	2		1		1		1		1		1	
Endometrial cancer‡		4	2	4	2	1		1		1		1	
Endometrial hyperplasia		1		1		1		1		1		1	
Endometriosis		2		1		1		1		1		1	
Epilepsy‡	(*see also Drug Interactions*)	1		1		1*		1*		1*		1*	
Gallbladder disease	a) Symptomatic												
	i) Treated by cholecystectomy	1		2		2		2		2		2	
	ii) Medically treated	1		2		2		2		2		3	
	iii) Current	1		2		2		2		2		3	
	b) Asymptomatic	1		2		2		2		2		2	
Gestational trophoblastic disease‡	a) Suspected GTD (immediate postevacuation)												
	i) Uterine size first trimester	1*		1*		1*		1*		1*		1*	
	ii) Uterine size second trimester	2*		2*		1*		1*		1*		1*	
	b) Confirmed GTD												
	i) Undetectable/non-pregnant ß-hCG levels	1*	1*	1*	1*	1*		1*		1*		1*	
	ii) Decreasing ß-hCG levels	2*	1*	2*	1*	1*		1*		1*		1*	
	iii) Persistently elevated ß-hCG levels or malignant disease, with no evidence or suspicion of intrauterine disease	2*	1*	2*	1*	1*		1*		1*		1*	
	iv) Persistently elevated ß-hCG levels or malignant disease, with evidence or suspicion of intrauterine disease	4*	2*	4*	2*	1*		1*		1*		1*	
Headaches	a) Nonmigraine (mild or severe)	1		1		1		1		1		1*	
	b) Migraine												
	i) Without aura (includes menstrual migraine)	1		1		1		1		1		2*	
	ii) With aura	1		1		1		1		1		4*	
History of bariatric surgery‡	a) Restrictive procedures	1		1		1		1		1		1	
	b) Malabsorptive procedures	1		1		1		1		3		COCs: 3 P/R: 1	
History of cholestasis	a) Pregnancy related	1		1		1		1		1		2	
	b) Past COC related	1		2		2		2		2		3	
History of high blood pressure during pregnancy		1		1		1		1		1		2	
History of Pelvic surgery		1		1		1		1		1		1	
HIV	a) High risk for HIV	1*	1*	1*	1*	1		1		1		1	
	b) HIV infection					1*		1*		1*		1*	
	i) Clinically well receiving ARV therapy	1	1	1	1	If on treatment, see Drug Interactions							
	ii) Not clinically well or not receiving ARV therapy†	2	1	2	1	If on treatment, see Drug Interactions							

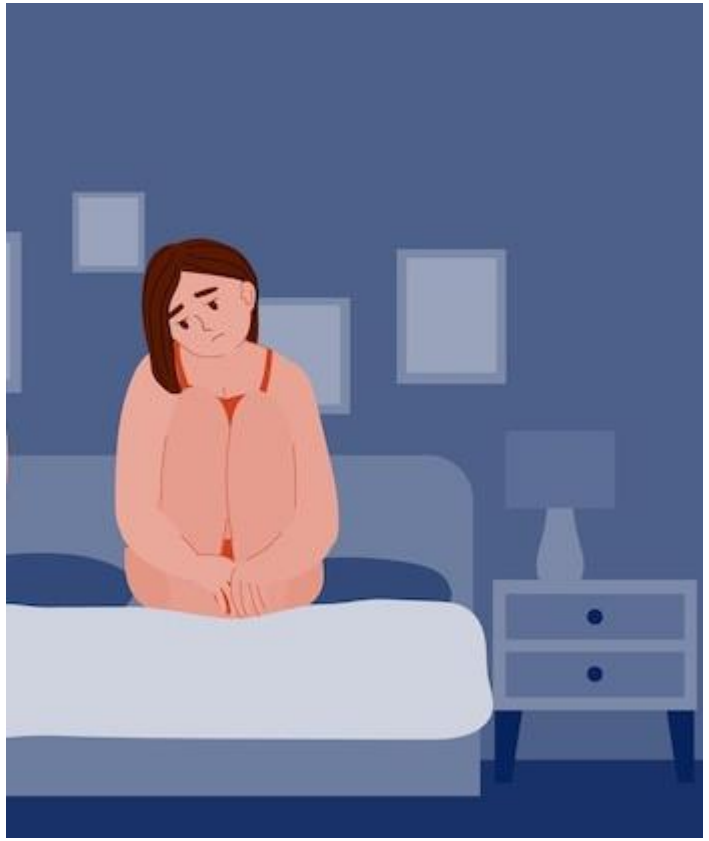
Key:

1 No restriction (method can be used)	3 Theoretical or proven risks usually outweigh the advantages
2 Advantages generally outweigh theoretical or proven risks	4 Unacceptable health risk (method not to be used)

Abbreviations: ARV = antiretroviral; C=continuation of contraceptive method; CHC=combined hormonal contraception (pill, patch, and, ring); COC=combined oral contraceptive; Cu-IUD=copper-containing intrauterine device; DMPA = depot medroxyprogesterone acetate; I=initiation of contraceptive method; LNG-IUD=levonorgestrel-releasing intrauterine device; NA=not applicable; POP=progestin-only pill; P/R=patch/ring; SSRI=selective serotonin reuptake inhibitor; ‡ Condition that exposes a woman to increased risk as a result of pregnancy. *Please see the complete guidance for a clarification to this classification: https://www.cdc.gov/reproductivehealth/contraception/contraception_guidance.htm

Sexual dysfunction

- Among women with disabilities, problems with sexual function can occur as a direct result of the disabling condition or indirectly, through mental and emotional reactions, such as diminished sexual self-esteem or low desire
- Women with disabilities may feel that sexual expression is limited by pain, weakness, fatigue, concerns about safety, and body image
- Among women with SCIs, the two most common sexual problems were lack of enjoyment (45%) and difficulty with positioning (42%). Among women with physical disabilities, 20% to 40% report problems with low arousal or vaginal dryness
- Muscular spasticity, common in cerebral palsy, multiple sclerosis, and SCI, can interfere with sexual activity

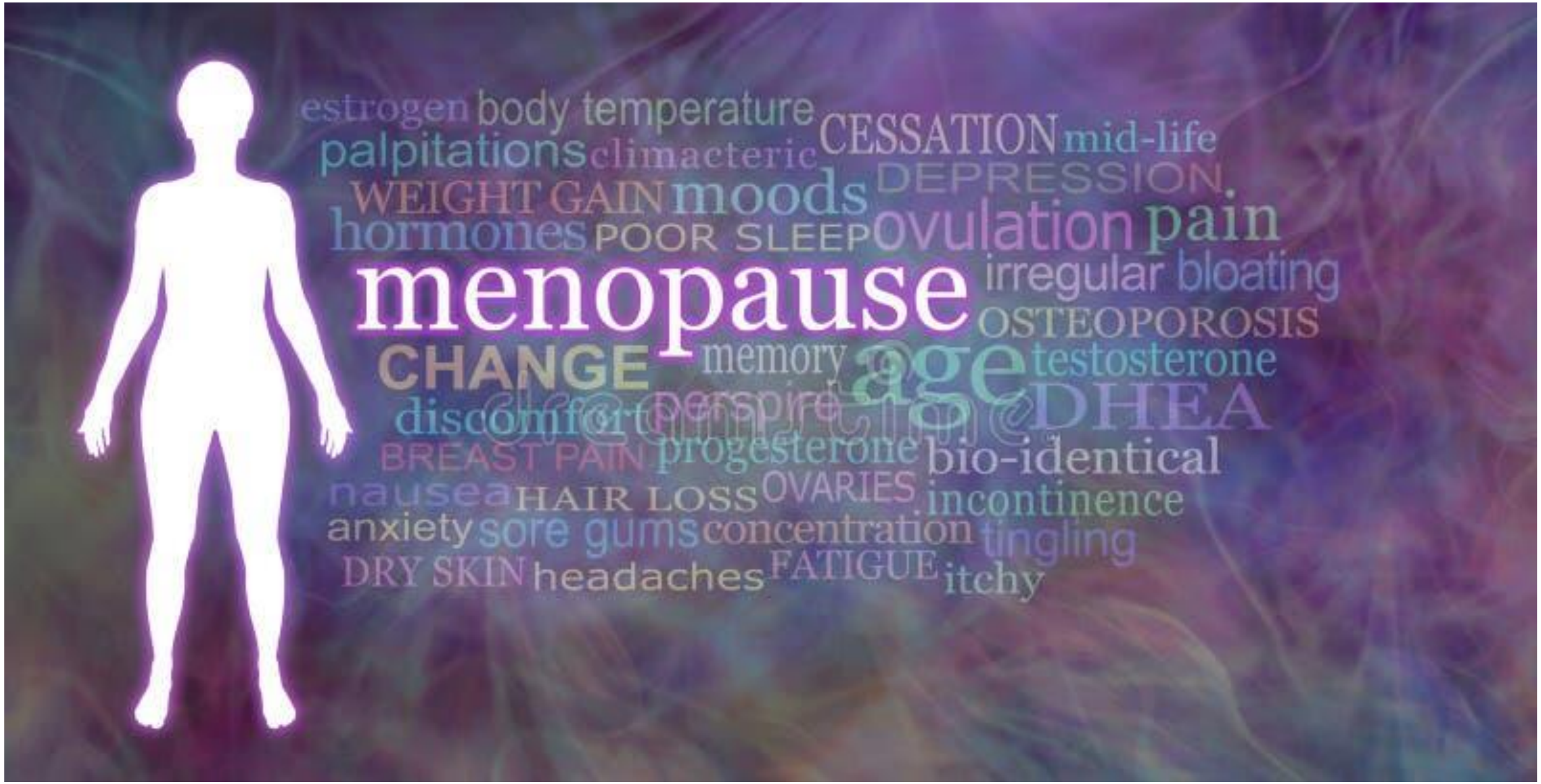


Signore. American Psychological Association. 2016

Abuse

- Awareness of abuse and domestic violence issues.
- One study found that one in three adults with intellectual disability suffers sexual abuse in adulthood.
- Special attention should be paid for early detection and intervention in high risk situations.
- Health care providers can prevent prolonged domestic violence or abuse situations.
- Women with disabilities tend to remain in abusive relationships longer than women without
- Conduct at least part of the visit with the woman alone and include questions about abuse in assessment.

Tomsa *et al*. Int J Environ Res Public Health 2021
Schopp *et al*, Journal of Midwifery and Women's Health 2010


estrogen
body temperature
palpitations
climacteric
CESSATION
mid-life
DEPRESSION
WEIGHT GAIN
moods
hormones
POOR SLEEP
ovulation
pain
menopause
irregular
bloating
OSTEOPOROSIS
CHANGE
memory
age
testosterone
perspire
discomfort
DHEA
BREAST PAIN
progesterone
bio-identical
nausea
HAIR LOSS
OVARIES
incontinence
anxiety
sore gums
concentration
tingling
DRY SKIN
headaches
FATIGUE
itchy

Menopause effect on disabilities

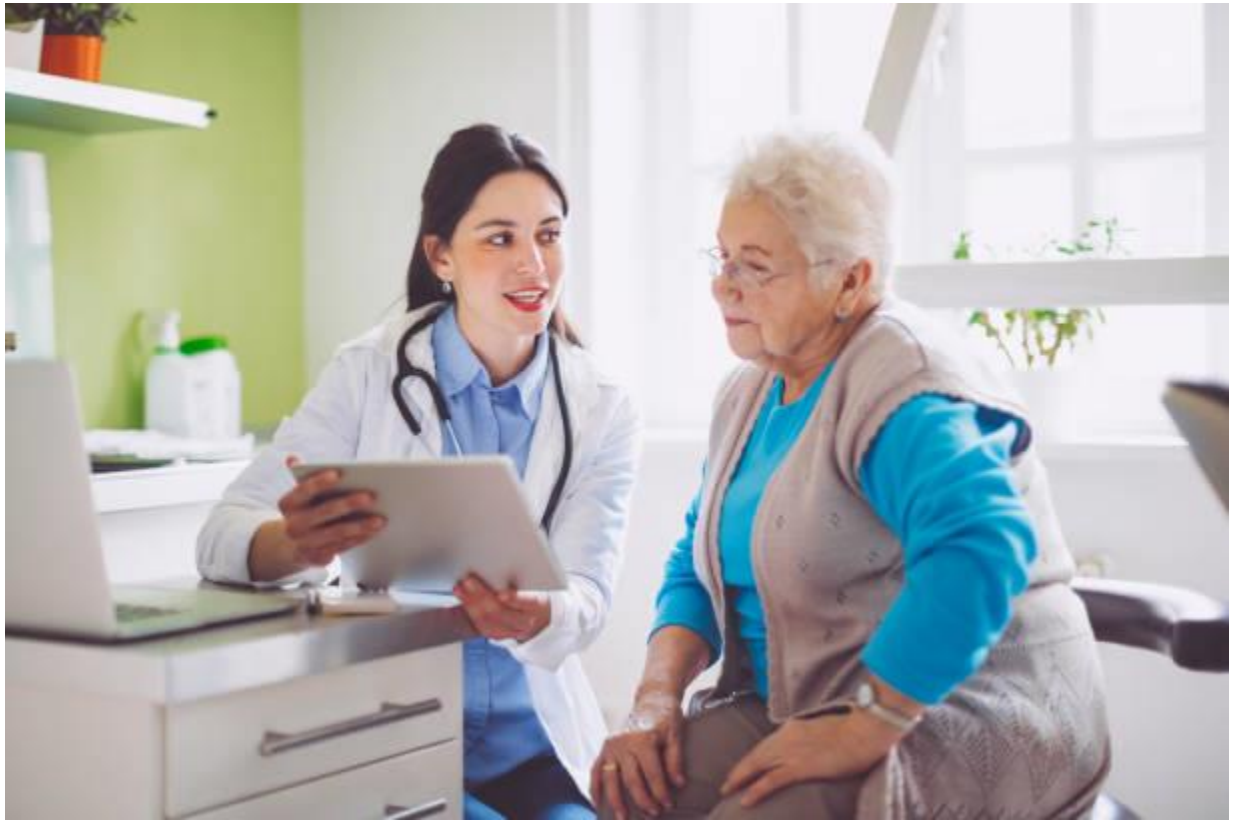
- Women with disorders that are sensitive to variations in estrogen levels may note worsening of disease manifestations during menopause.

Menopausal Issues

- Menopause in women with disabilities has not been widely studied
- There is little data of the experiences of women with intellectual disabilities in menopause.
- Like all women, those with disabilities are at risk for osteoporosis after menopause.
- Use of hormone replacement therapy (HRT) in women with disabilities should be a careful clinical decision

Schopp *et al*, Journal of Midwifery and Women's Health 2010

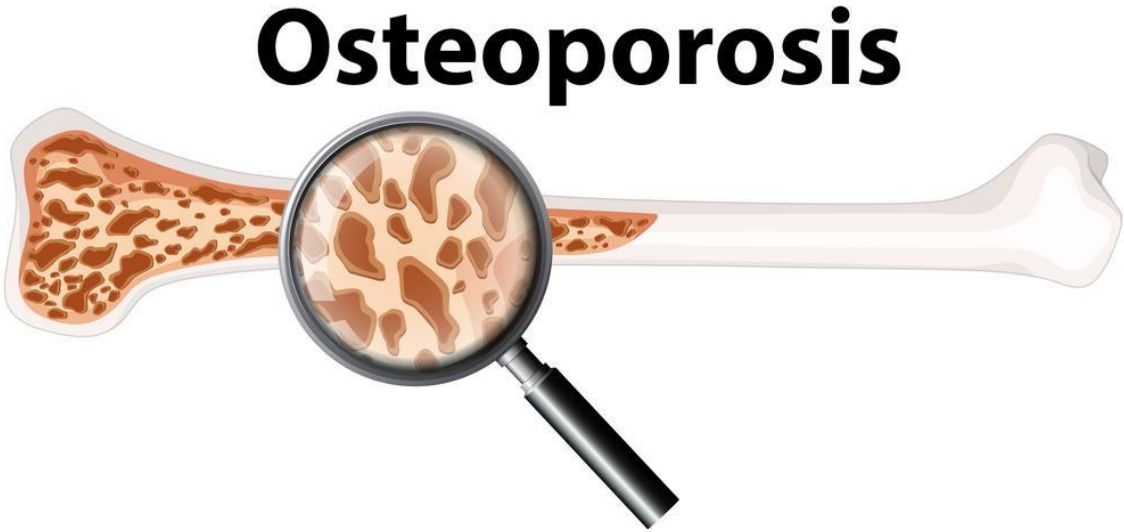
Menopausal Issues



- Aging is also associated with a higher incidence of malignancies.
- Women with disabilities are less actively screened for cancer.
- Developing strategies by which menopausal women with disabilities can be successfully evaluated and treated for preventable conditions is essential to maximizing their health.

Screening for osteoporosis

- Osteoporosis is one of the most commonly reported, yet frequently ignored secondary conditions in women with disabilities.
- The few studies that address osteoporosis in women with disabilities have revealed a high incidence of low BMD
- The rate of falls and injuries in people with disabilities has been reported to range from 4-10 times that of the general population.
- Risk factors help identify who should be referred for screening
- No recommendations about BMD screening for women with disabilities have been developed.
- It is not known if screening, diagnostic testing, treatment and prevention strategies differ for women across disabilities.
- Criteria for a diagnosis of osteopenia and osteoporosis in women with disabilities need to be identified



Smeltzer. Family & Community Health 2006

Breast cancer screening

- Breast cancer is the most frequent type of cancer in women and is the second highest cause of cancer deaths in the United States (U.S. Cancer Statistics Working Group, 2013).
- Breast cancer mortality rates have decreased: the current 5-year survival rate is 90%, which is higher than the 5-year survival rate of 75% in 1975.
- This decrease has been attributed to early detection and improvements in breast cancer treatment

ACOG Practice Bulletin #179 Breast Cancer Risk Assessment and Screening in Average-Risk Women 2017

Breast cancer screening

Table 1. Recommendations for Breast Cancer Screening in Average-Risk Women

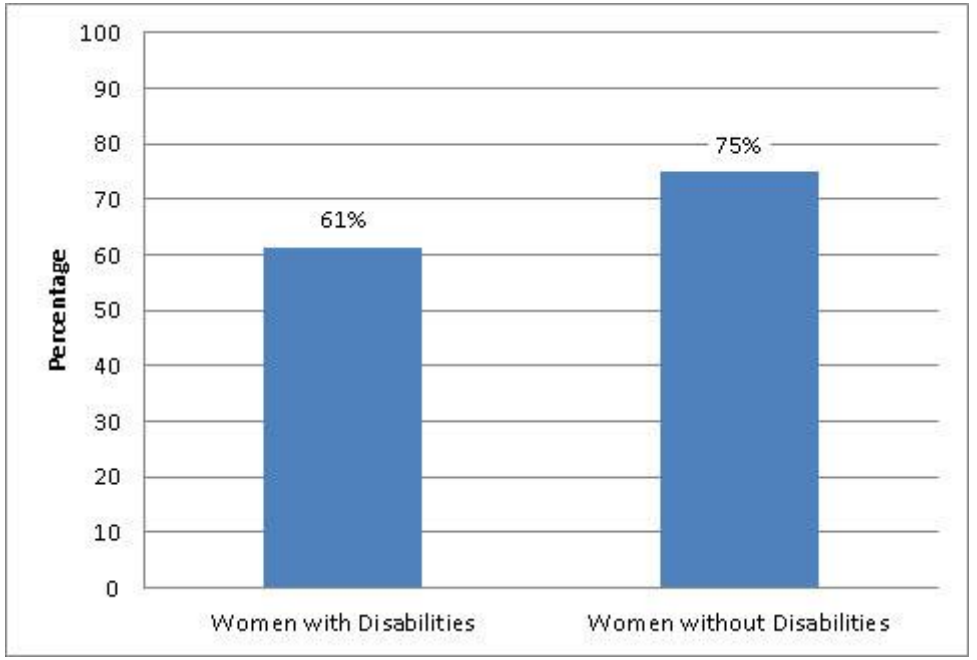
	American College of Obstetricians and Gynecologists	U.S. Preventive Services Task Force	American Cancer Society	National Comprehensive Cancer Network
Clinical breast examination	May be offered* every 1–3 years for women aged 25–39 years and annually for women 40 years and older.	Insufficient evidence to recommend for or against.†	Does not recommend‡	Recommend every 1–3 years for women aged 25–39 years. Recommend annually for women 40 years and older.
Mammography initiation age	Offer starting at age 40 years.§ Initiate at ages 40–49 years after counseling, if patient desires. Recommend by no later than age 50 years if patient has not already initiated.	Recommend at age 50 years.‖ Age 40–49 years: The decision to start screening mammography in women before age 50 years should be an individual one.¶	Offer at ages 40–45 years.¶ Recommend at age 45 years.#	Recommend at age 40 years.
Mammography screening interval	Annual or biennial§	Biennial‖	Annual for women aged 40–54 years‡ Biennial with the option to continue annual screening for women 55 years or older‡	Annual
Mammography stop age	Continue until age 75 years. Beyond age 75 years, the decision to discontinue should be based on a shared decision-making process that includes a discussion of the woman's health status and longevity.	The current evidence is insufficient to assess the balance of benefits and harms of screening mammography in women 75 years and older.†	When life expectancy is less than 10 years‡	When severe comorbidities limit life expectancy to 10 years or less

ACOG Practice Bulletin #179 Breast Cancer Risk Assessment and Screening in Average-Risk Women 2017

Breast cancer screening

- Women with disabilities face persistent disparities in breast cancer screening, diagnosis, treatment, and outcomes
- Studies also show higher rates of death related to breast cancer among women with a disability, even when diagnosed at the same stage as women without a disability

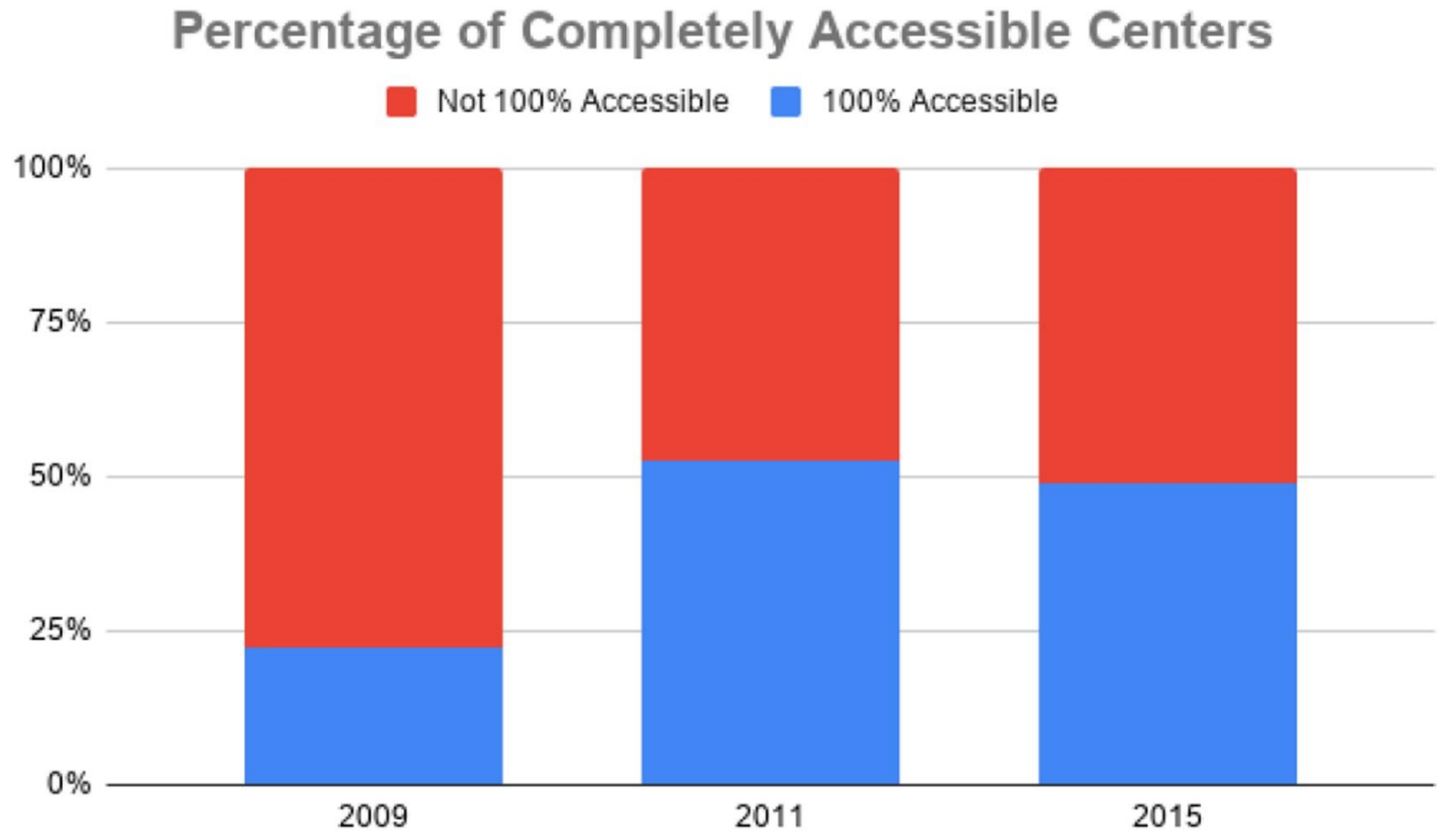
Percentage of U.S. Adult Women 50-74 Years of Age Who Received a Mammogram During the Past 2 Years, By Disability Status – 2010 National Household Interview Survey(NHIS)



CDC/NCHS. National Health Interview Survey Data, 2010.

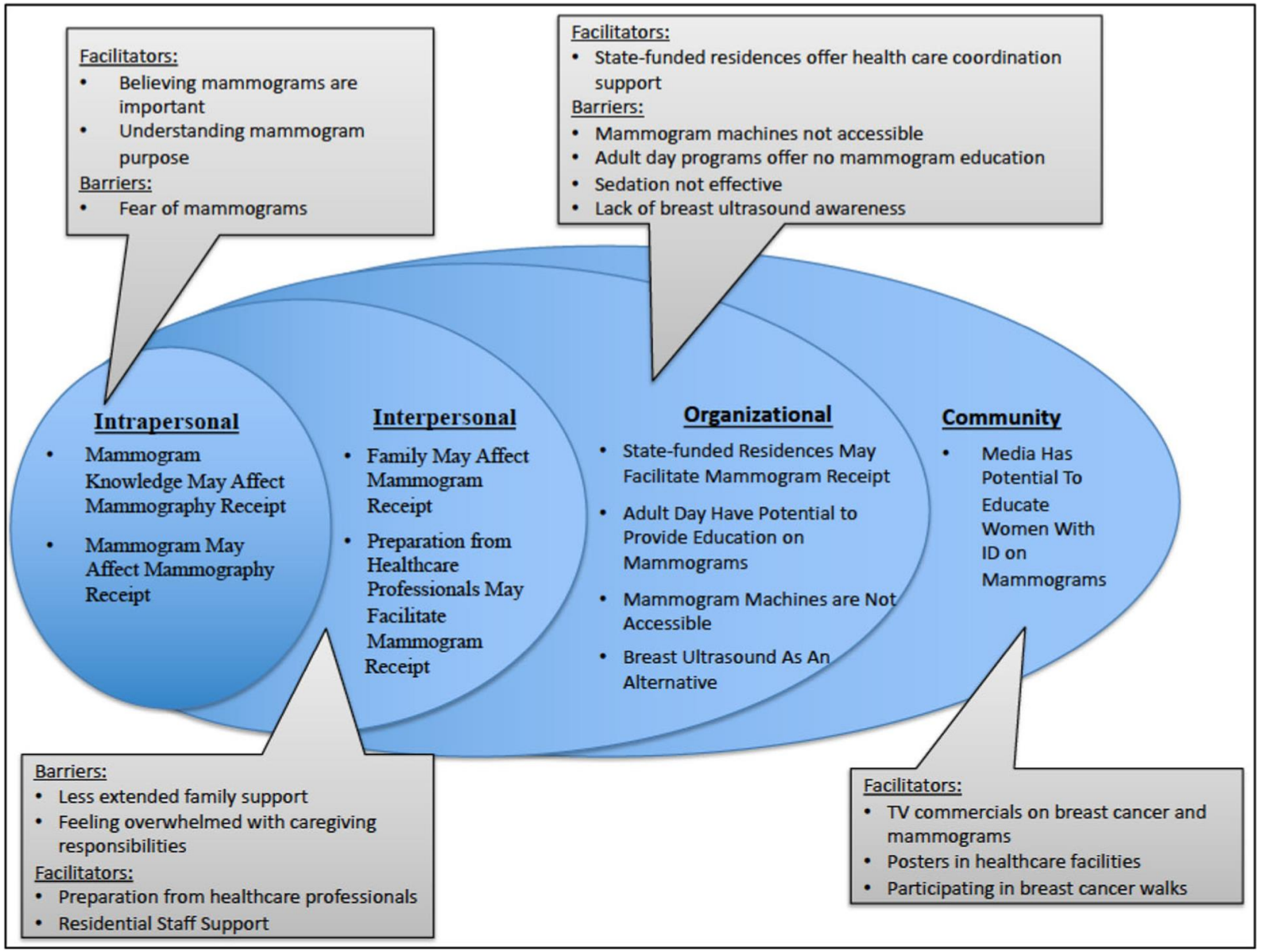
Centers for Disease Control and Prevention's Right to Know campaign

Presence of completely accessible Montana Mammography Centers (2009–2015)



Traci MA, *et al*. Front Womens Health. 2020

Barriers and facilitators to mammography



Arana-Chicas *et al*
Disability& Society
2020

Cervical cancer screening

Woman's **Age**	**How often** should a woman have a Pap test?
under 21 years old	No testing needed
21-30 years old	Pap test **every 3 years**
30-65 years old	Pap test **every 3 years** or Pap and HPV **every 5 years**
65 years old or older	No testing needed

NY State Department of Health www.health.ny.gov/diseases/cancer/cervical/campaign/

Pap test screening

- Studies have repeatedly shown that women with disabilities receive cervical cancer screening at rates lower than their nondisabled peers (Chan et al., 1999).
- Women with physical disabilities were significantly less likely to report receiving a Pap smear in the past year compared to those without physical disabilities.
- One national study found that women with intellectual disabilities were 72% less likely than women without disabilities to have received screening for cervical cancer (Parish, 2006)
- Commonly reported barriers include inaccessible practitioner offices and equipment and a lack of accessible and convenient transportation
- Data from the National Health Interview Survey indicate that these disparities in screening extend to women with sensory, mental, cognitive, or social disabilities as well (Drew & Short, 2010).
- Women with cervical cancer with disabilities, especially severe disabilities, were diagnosed with more advanced stage or unknown stage of cervical cancer, received less treatment, and had higher overall mortality than those without disabilities.

Choi *et al*. Cancer Control. 2021

Human papillomavirus (HPV) vaccination

- HPV vaccine is recommended for routine vaccination at age 11 or 12 years.
- ACIP and CDC also recommends vaccination for everyone through age 26 years. And vaccine is FDA approved to age 45
- The HPV vaccination rates among 9–26 years special needs females are lower than general population

MacLeod and Tuffrey. Archives of Disease in Childhood 2014

Initiative for Women with Disabilities at New York University

- IWD is one of only a handful clinics in the country dedicated to providing gynecological care to women with disabilities. Our staff is committed to providing compassionate patient care
- Offer routine well woman examinations and Pap smears as well as consultations on gynecologic conditions
- Patients benefit from access to our social worker, and wellness programs, workshops and classes.

NYU Langone MEDICAL CENTER

Pelvic Examination

Preparation of the patient:

- Explain ahead of time
- Role play
- Define desired behavior
- A tour visit of the office and examination room
- A familiar person to accompany the patient.

Preparation of the office staff:

- Schedule on uncrowded days
- Plan for a short waiting time
- Schedule a series of appointments
- Provide staff for continuity
- Explain procedure calmly and in a soft voice
- Know that the procedure may take longer
- Consider use of antianxiolytic

Other considerations:

- Use a narrow speculum such as a Pederson for virginal patients
- May use a cytobrush "blindly" to sample the os
- Consider use of pelvic ultrasound if a bimanual examination cannot be done
- Rarely a patient will require general anesthesia.

Witemeyer. GYN Exam & Mammograms for Women with Developmental Disabilities https://hsc.unm.edu/medicine/departments/pediatrics/divisions/continuum-of-care/pdf/gyn-mammogram-exams-for-dev-disabled.pdf

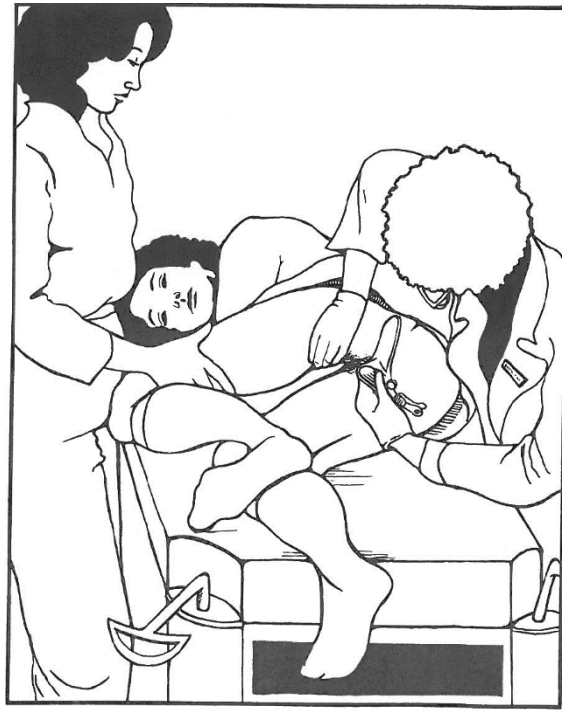
Pelvic Exam

- A pelvic examination may need to be modified.
- women with disabilities often experience more pain and/or discomfort than other women during the examination. This discomfort can be reduced by using different methods of positioning

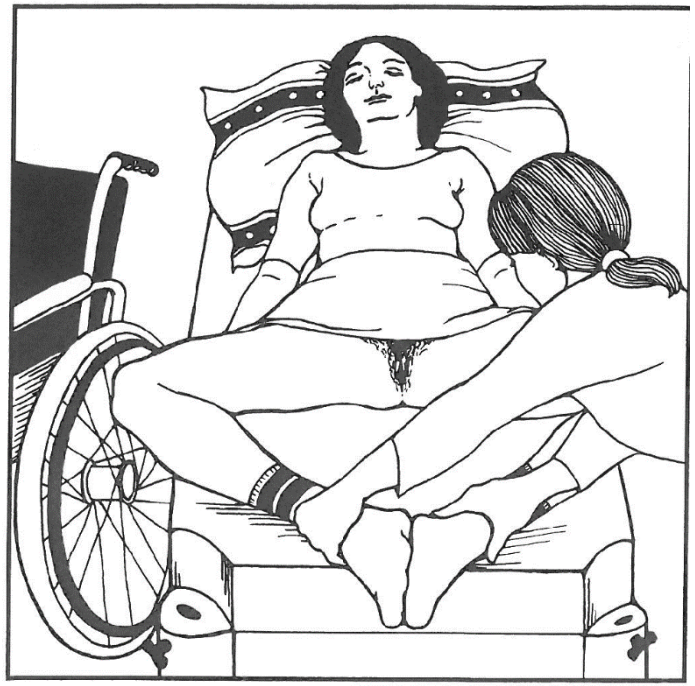
Schopp *et al*, Journal of Midwifery and Women's Health 2010

Modified pelvic exam

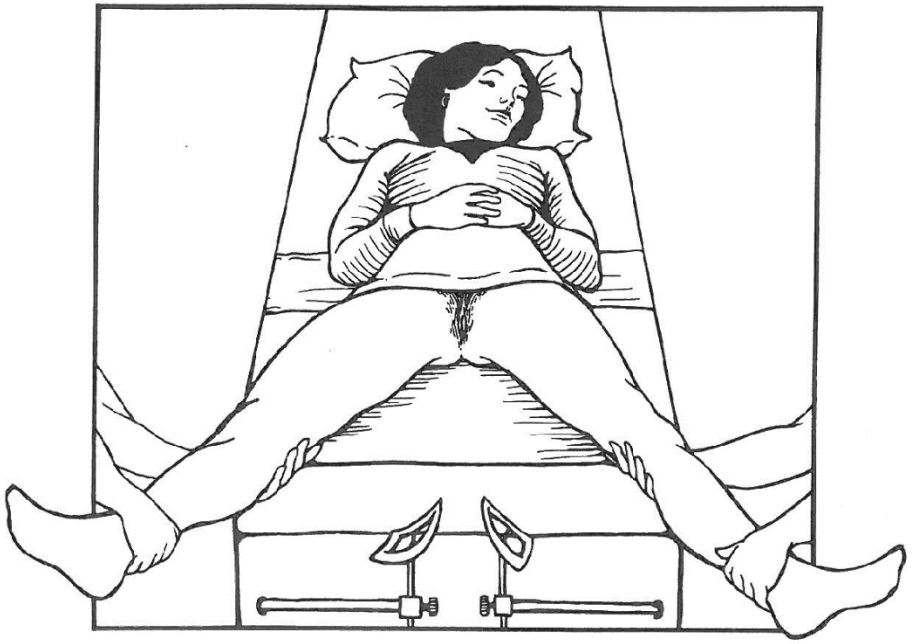
Knee-chest



Diamond shaped



V shaped



Ferreyra and Hughes. Table Manners: A Guide to the Pelvic Examination for Disabled Women and Health Care Providers. 1984

An accessible future

- Women's health care providers require training and support to enable them to offer effective services to all of their patients, regardless of disability.
- Health care providers can serve as powerful advocates for women with disabilities.
- Given appropriate tools, health care providers can ensure that high-quality GYN care is accessible to all women.
- And other providers play critical roles in recommending use of these gynecologic services to their patients

Thank you!

NYU Langone MEDICAL CENTER