



Direct Support Professionals



Intellectual/Developmental Disability and Complex Care Needs

Individuals with IDD and co-occurring mental illness, medical illness and/or challenging behavior

Gyn Care for People with IDD

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Objectives

- **PREPARING FOR MENSES**
- **CERVICAL CANCER SCREENING**
- **MAMMOGRAMS**

SEXUALITY AND VULNERABILITY

- Adolescents with I/DD have typical sexual development
- Higher risk of abuse, coercion, and unprotected sex
- Need for developmentally appropriate sexual education

PREPARING FOR MENSES

- Core principle: start with standard menstrual care for all women.
- Adapt for communication, understanding, and support needs.
- Reframe “problem menstruation” as gaps in preparation, accessible education, and practical supports—rather than disability itself.



PREPARING FOR MENARCHE

Start early

Prepare well before first bleeding to reduce fear and confusion.

Teach concretely

Use simple language, repetition, visual supports, and hands-on practice with pads.

Normalize and support

Families and educators reinforce skills; many challenges are preventable with education.

USING A PAD

PUBERTY SKILLS STORY

The bottom of the pad will have a sticker.
I pull off the sticker.



Now the bottom of the pad is sticky.
This helps it to stick to my underwear.



There are many different types
of pads.



Some pads are short.



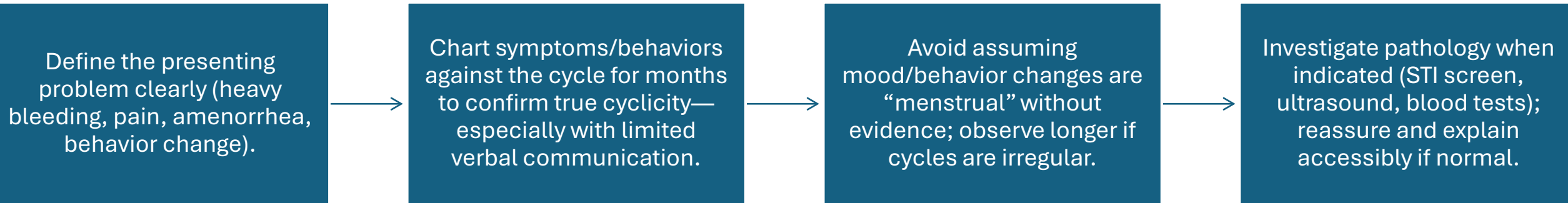
Some pads are long.



ASSESSMENT MENSTRUAL PROBLEMS



ASSESS MENSTRUAL ISSUES





COMMON MENSTRUAL CONCERNS

- Dysmenorrhea (painful) and heavy bleeding are common—quantify with concrete questions (e.g., pads/day).
- Amenorrhea: primary may relate to underweight status or neurological conditions; secondary is often pregnancy.
- Always consider pregnancy regardless of disability status.
- Menstrual patterns may reflect epilepsy (catamenial), genetic syndromes with hypogonadism, weight/thyroid extremes, or medications (antipsychotics/anticonvulsants).



MANAGING CYCLIC ISSUES

Behavior, pain, and amenorrhea workup

Cyclic behavioral change

In some women with intellectual disability, pain may present mainly as irritability, aggression, or withdrawal. Educate the woman and support network to link possible pain with behavior, and avoid misattribution.

Management approach

Start with non-pharmacological foundations: regular physical activity, stress management, and healthy routines. If dysmenorrhea is suspected, trial standard analgesia while charting behavior to assess response.

Amenorrhea: systematic evaluation

Investigate delayed puberty at age 14 and delayed menarche at age 16. For secondary amenorrhea, consider pregnancy first, then assess weight change, endocrine causes, medication effects, and major psychological stress.

Goals of Menstrual Management

1

Reduce pain,
bleeding, and
behavior disruption

2

Support hygiene
and quality of life

3

Complete
suppression not
always necessary or
desired

Non-Hormonal Management

NSAIDs for pain and
reduced bleeding

Tranexamic acid for heavy
menstrual bleeding

Consider VTE risk and
comorbidities

Hormonal Options

- Combined hormonal contraception (often continuous)
- Oral progestins or DMPA
- Levonorgestrel IUD increasingly favored

Comparing characteristics between contraceptives:	Efficacy against pregnancy	Convenience (when used for daily protection)	Best to maintain periods	Best to achieve amenorrhea (no periods)	Best to reduce acne
 Implant	✓✓✓	✓✓✓	✓✓✓	✓✓✓	✗
 Hormonal Coil / IUS	✓✓✓	✓✓✓	✓✓✓	✓✓✓	✗
 Copper Coil / IUD	✓✓✓	✓✓✓	✓✓✓	✗	✗
 Injection (DMPA)	✓✓✓	✓✓✓	✓✓✓	✓✓✓	✗
 Combined Pill	✓✓✓	✓✓✓	✓✓✓	✓✓✓	✓✓✓
 Mini Pill	✓✓✓	✓✓✓	✓✓✓	✓✓✓	✗
 Patch	✓✓✓	✓✓✓	✓✓✓	✓✓✓	✓✓✓
 Vaginal Ring	✓✓✓	✓✓✓	✓✓✓	✓✓✓	✓✓✓
 Condoms	✓✓✓	✓✓✓	✓✓✓	✗	✗

What to Expect During an IUD Insertion

1.

Doctor performs bimanual pelvic exam and determines position of uterus

2.

Vagina is opened and cervix is cleaned and stabilized



3.

Doctor uses a device called a “sound” to measure length and direction of cervical canal and uterus



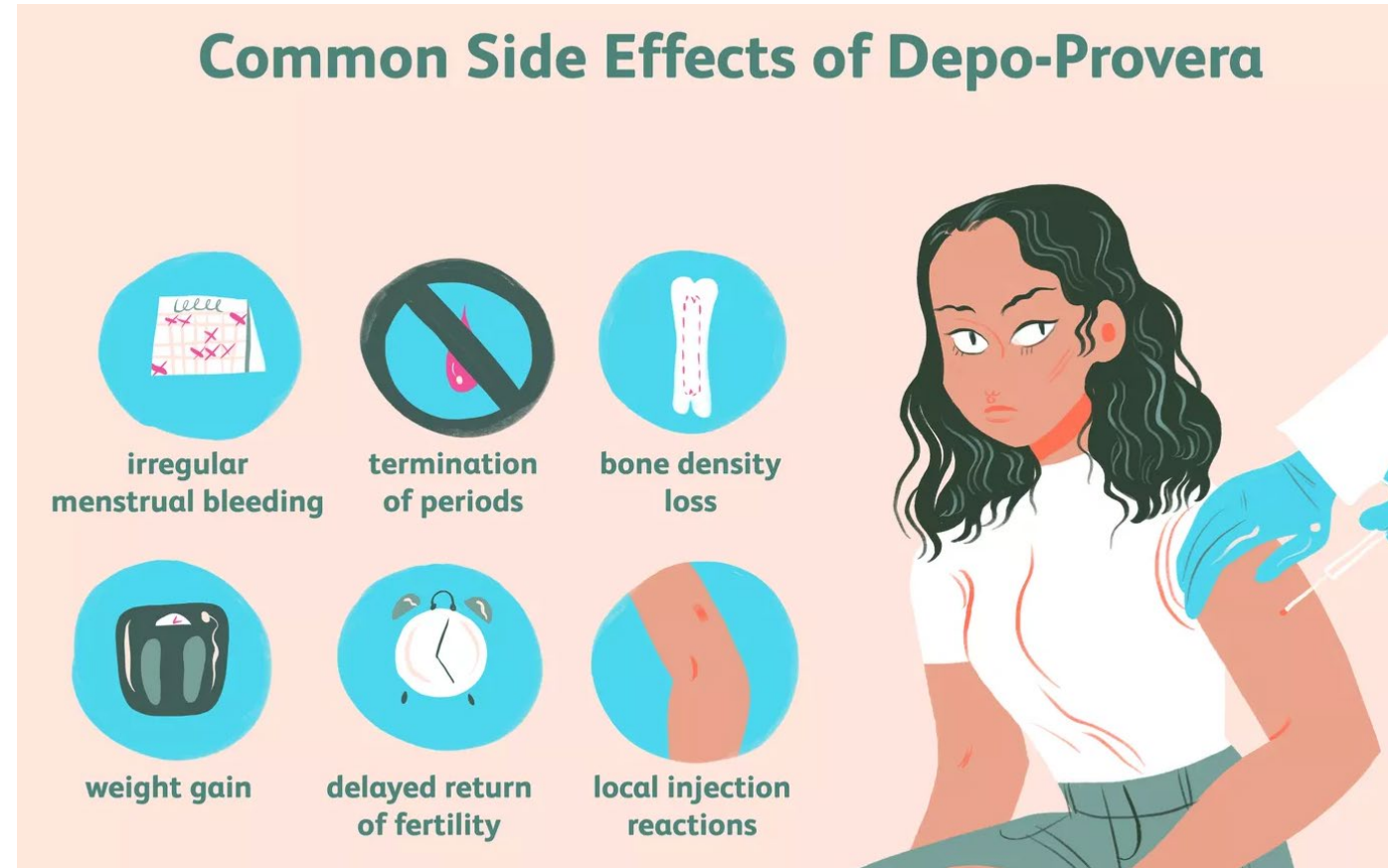
4.

IUD is pushed into place, instruments are removed, and doctor cuts ends of strings



SPECIAL CONSIDERATIONS

- Epilepsy and catamenial seizures – May need to consider IUD
- Bone mineral density concerns – Chronic use of depo shot, certain medications can increase risk of osteoporosis
- Medication interactions (AEDs, antipsychotics)





CONSENT & CAPACITY

Legal frameworks and safeguards

Capacity is decision-specific: the person must understand, retain, weigh, and communicate relevant information.

Most women with mild intellectual disability can consent to menstrual-disorder treatment when information is accessible.

If capacity is lacking, a legally recognized substitute decision-maker may be required; paid carers cannot consent.

Irreversible procedures (e.g., sterilization, pregnancy termination) require court/tribunal approval; abuse of this is a crime.

WORKING WITH DSP/Support team

Communicate clearly

Use jargon-free language and confirm the support person's familiarity with the woman, especially where staff turnover is high.

Document for continuity

Provide a written plan covering diagnosis, investigations, treatment, expected outcomes, and potential side effects.

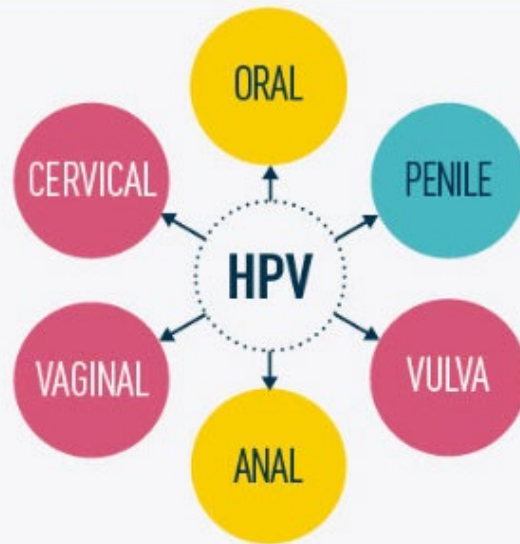
Keep the woman central

Review regularly to ensure implementation and effectiveness, supporting dignity, autonomy, and quality of life.

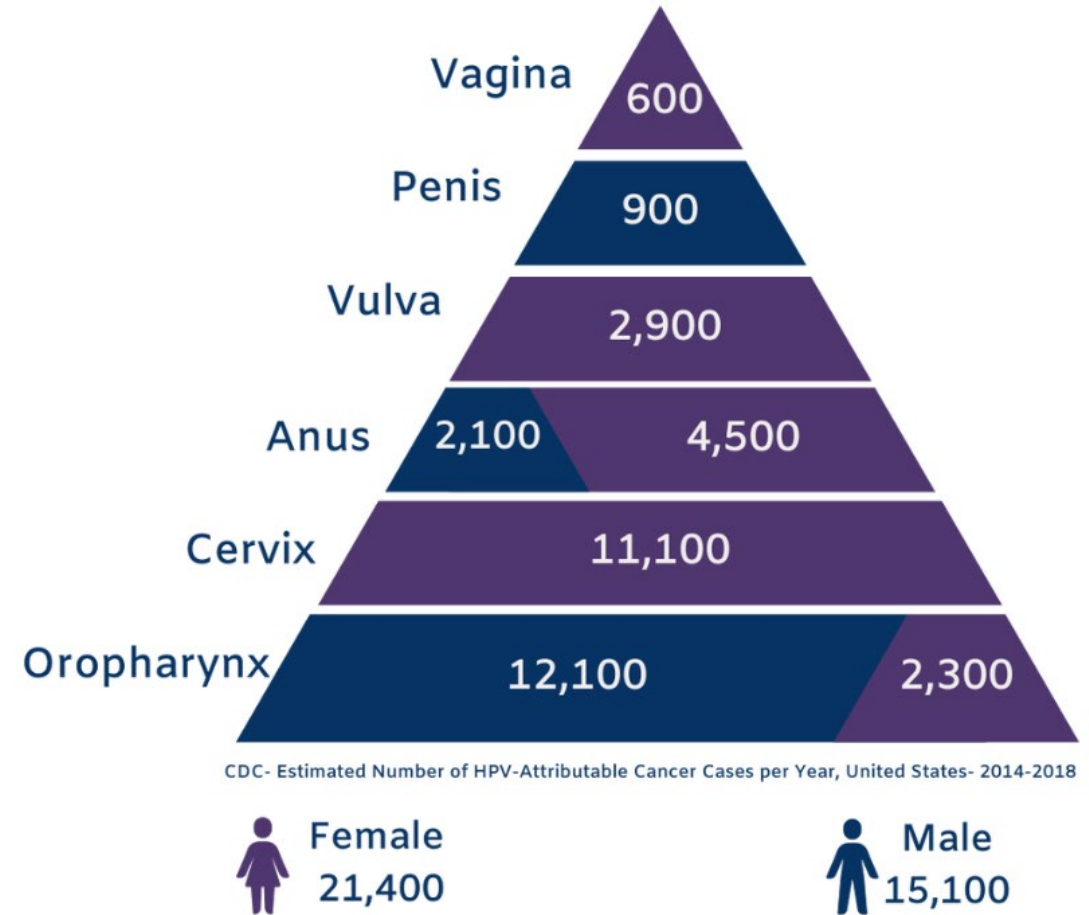


HPV CAUSES CANCER

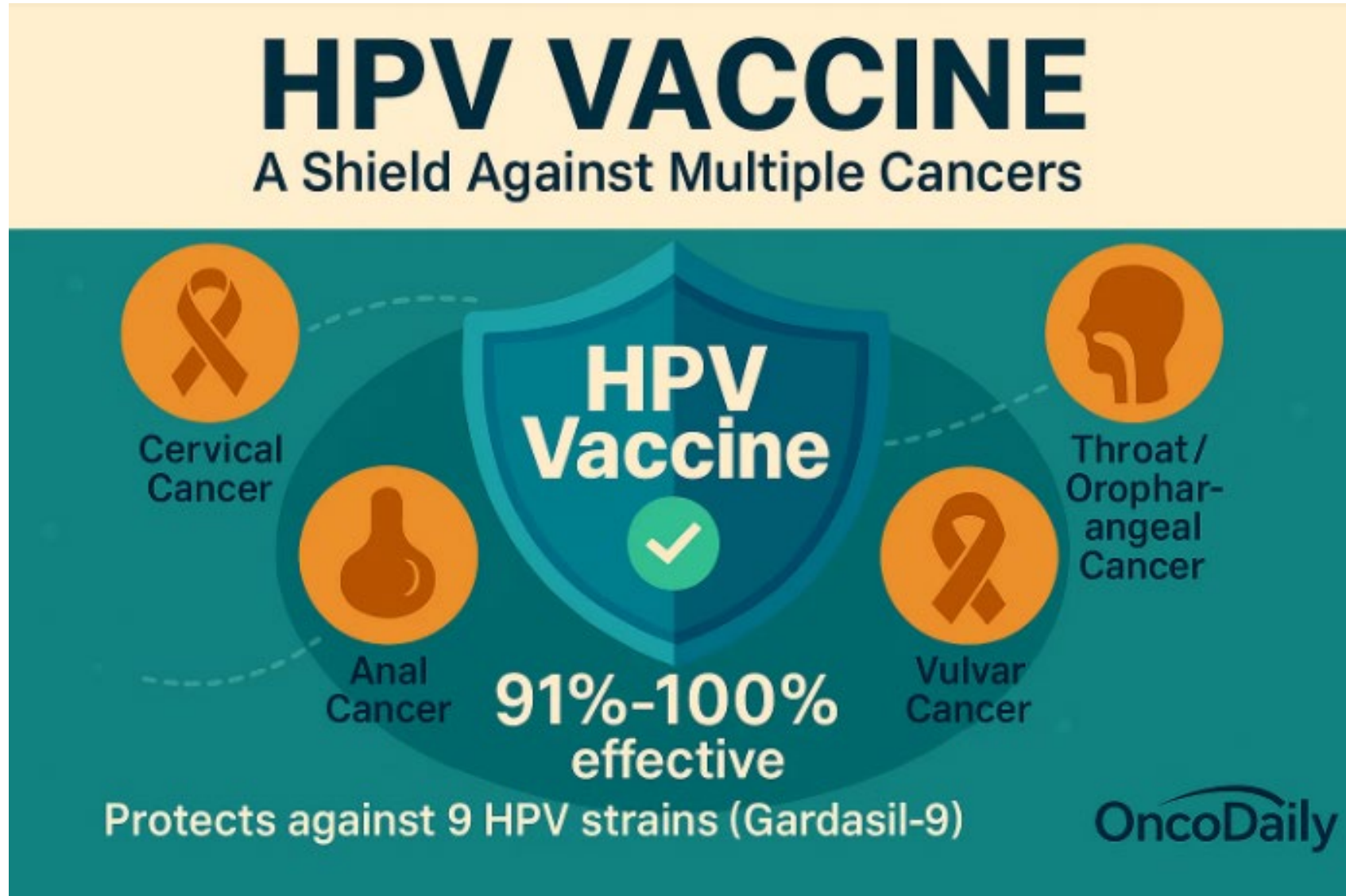
HUMAN PAPILLOMAVIRUS CAN CAUSE SEVERAL TYPES OF CANCER



cancer.gov/hpv



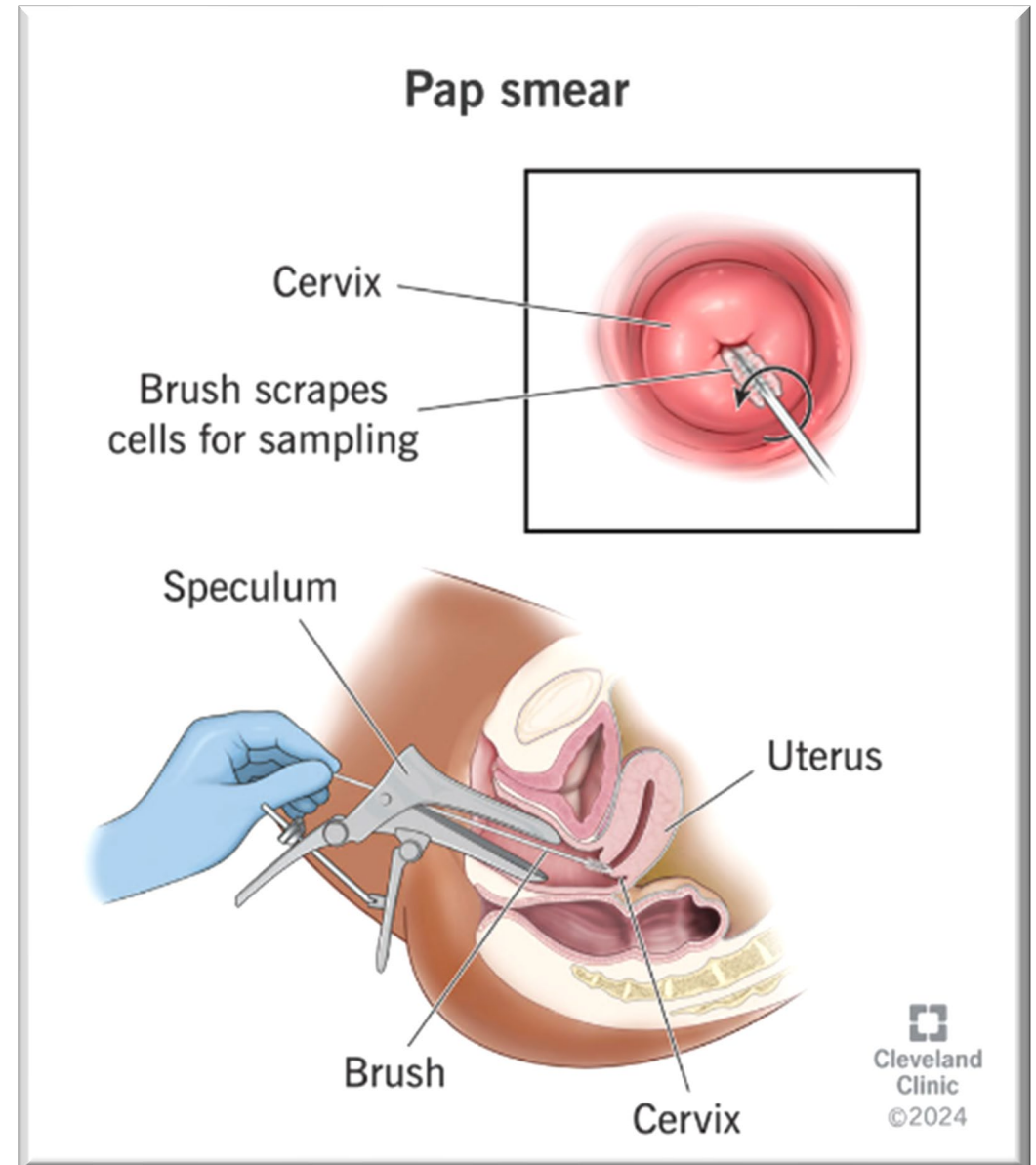
HPV Vaccine- offer at 9, can get up to 45!



CERVICAL CANCER SCREENING

What is a pap smear?

- ❑ A Pap smear (also called a Pap test) screens for cervical cancer. The test checks for abnormal cells on your cervix that are cancerous or have the potential to become cancerous and may also detect certain infections and inflammation.
- ❑ Healthcare providers consider a Pap smear to be the gold standard for preventing cervical cancer because it detects cervical cell changes *before* they can turn into cancer.



Disparity in cervical cancer screening

- Usually requires sedation
- Trying to coordinate care with other tests (blood, dental)
- Spasm in legs or use of wheelchair can make the pap smear more uncomfortable

Coming this year!!!!
Self Swab

U How do I use the Lancet Evalyn -Brush*



1

Remove the Evalyn-Brush from the packaging. Do not throw the packaging away, as it is necessary for sending the Evalyn-Brush to the laboratory after usage.



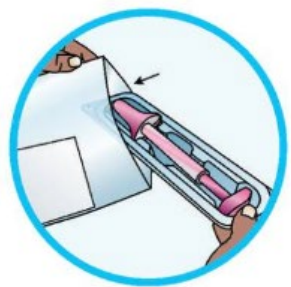
2

Press the sides of the pink cap with your thumb and index finger to remove the pink cap from the Evalyn-brush. Ensure that you do not touch the white fibres of the Evalyn-brush with your hands!



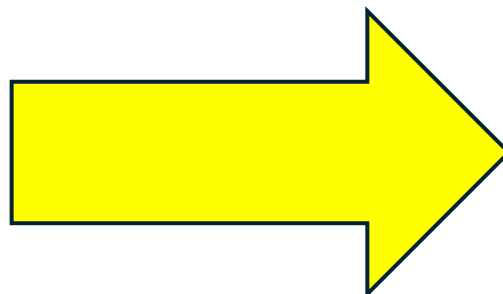
3

Insert the Evalyn-brush up to the wings, push the plunger rotate x 5. Carefully remove the Evalyn-brush and replace the pink cap.



4

Place the Evalyn-Brush back inside the original package. Put the package containing the Evalyn-Brush into the plastic bag provided, seal it then submit to the laboratory.



R Test Results

- Results are available within 1-2 days.
- Results can be sent via email
- Results interpretation assisted by a trained staff
- The prevalence of HR-HPV in Kenya ranges from 5-20% among HIV-ve women and 40-50% among those who are HIV+ve

M What do my HPV results mean?

- If the HPV test result is negative you are NOT at risk of developing cervical cancer and you do not need to test again for 3- 5 years.
- If the HPV test is positive, you need to see a gynecologist for further management
 - If positive for HPV 16 or 18, colposcopy should be done for biopsy and / or treatment on the spot.
 - If positive for any of the other 12 HR-HPV subtypes (other than 16 or 18), a PAP smear will be done to guide the gynecologist on further management.

Key References on HPV Testing:

- Gynecol Oncol. 2015 Feb;136(2):178-82.
- Obstet Gynecol. 2015 Feb;125(2):330-7.
- J Low Genit Tract Dis. 2015 Apr;19(2):91-6.

For more information, visit www.lancet.co.ke



ACS VERSUS USPSTF

Population age	ACS Recommendation	USPSTF Recommendation
<21 years	No screening	
21-25 years	No screening	Cytology every 3 years
25-29 years	Primary hrHPV testing every 5 years Secondary options include: • Co-testing every 5 years • Cytology every 3 years	Cytology every 3 years
30-65 years		Any one of the following: • Cytology every 3 years • Primary hrHPV testing every 5 years • Co-testing every 5 years
>65 years	No screening if certain criteria are met	
	Endorses ASCCP management guidelines	

Table 1. Comparison of Current Screening Options^{3,14,15}

	Advantages	Disadvantages
Cytology with reflex HPV testing	• Proven efficacy • Familiar to patients and providers	• Less sensitive than HPV testing • Requires repeat every 3 years to compensate for limited sensitivity
Cotesting	• Increased sensitivity • Repeat at 5-year intervals • May be more sensitive for adenocarcinomas	• Double the number of tests compared with primary HPV testing with little gain in sensitivity • Less familiar to patients and providers
Primary HPV testing	• Increased sensitivity • Repeat at 5-year intervals • May be more sensitive for adenocarcinomas	• Unfamiliar to patients and providers

Breast Cancer Screening in Adults with Intellectual & Developmental Disabilities

Background

Adults with IDD have similar breast cancer incidence to the general population

Mammography screening rates are significantly lower

Disparities contribute to later diagnosis and poorer outcomes

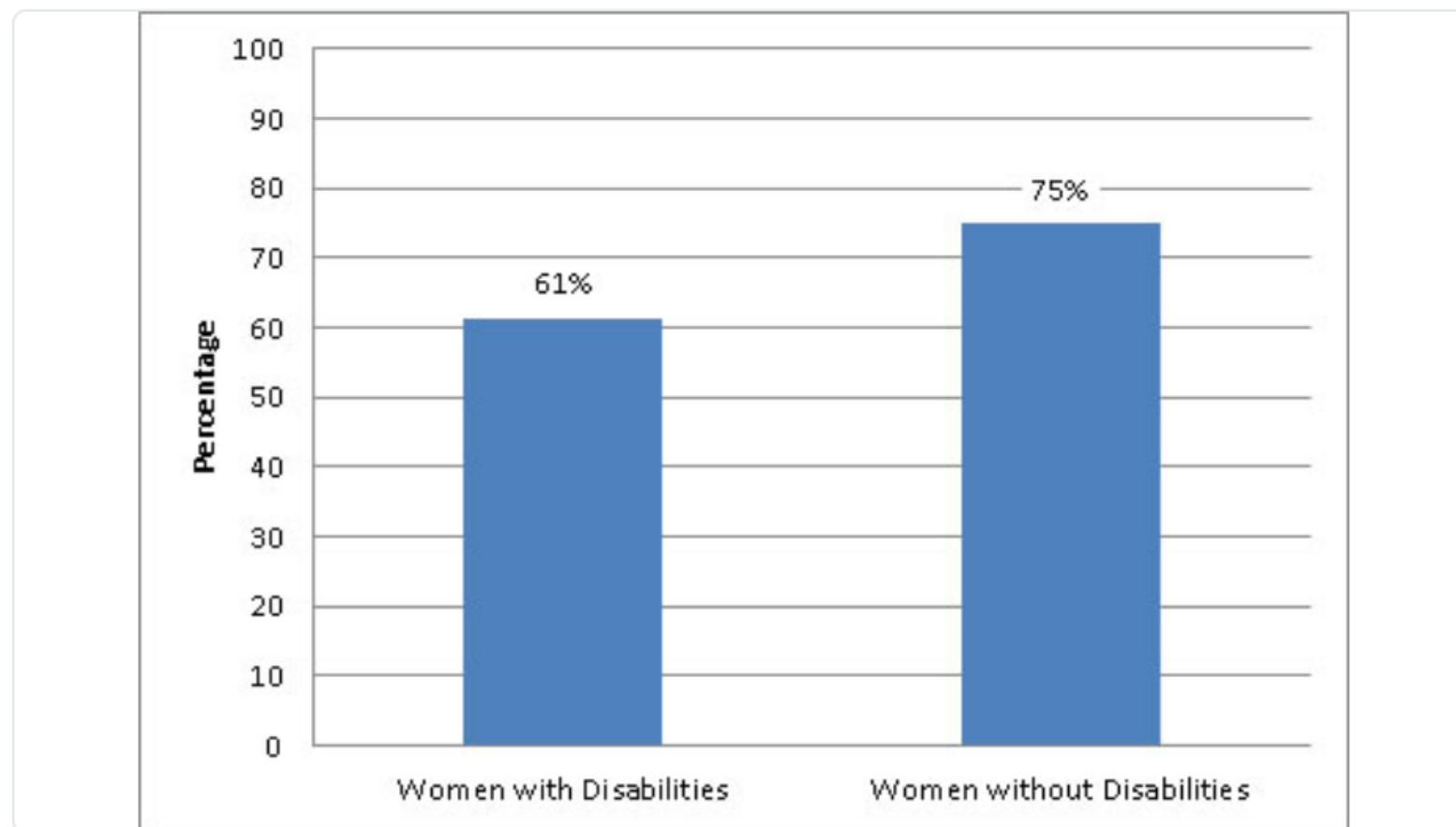
Breast Cancer Screening Disparities

Adults with IDD are ~1.5 times less likely to receive mammography

Barriers include communication challenges and sensory discomfort

Limited availability of accessible and supportive screening services

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)*



About 75% of women without disabilities received a mammogram during the past two years, while only 61% of women with disabilities did the same.

Common Challenges

Difficulty understanding
the procedure

Anxiety, fear, or sensory
sensitivity

Physical limitations
affecting positioning

Preparation & Communication

1

Explain the procedure in advance using clear, simple language

2

Use visual aids or easy-to-read materials

3

Allow time for questions and reassurance



Helen asks Lisa to remove her shirt and move to the front of the X-ray machine.

She touches Lisa and lifts her left breast into the X-ray machine.

Helen explains that it might be slightly uncomfortable.

Helen moves behind the screen.



Access & Accommodation Needs

- Wheelchair-accessible rooms and adjustable equipment
- Longer appointment times when needed
- Ability to perform mammography while seated

Role of Support Persons

Trusted caregiver
or advocate
present during
visits

Assists with
communication
and emotional
reassurance

Supports shared
decision-making

Strategies to Improve Access



Pre-appointment planning with the screening facility



Practice or familiarization visits when available



Individualized approach based on anxiety and sensory needs

Key Takeaways

Breast cancer screening disparities are preventable

Preparation, accommodation, and support are essential

Proactive planning can improve screening success and experiences