



Cervical Cancer Screening

General Guidelines, and Health Disparity Implications within the Intellectual/ Developmental Disability (IDD) Population



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Cervical Cancer Screening Guidelines (CCS) 2019:

The American Cancer Society: Women should follow these guidelines to help find cervical cancer early.

- * All women should begin cervical cancer testing (screening) at age 21.
- * Between the ages of 21 to 29, a Pap test should occur every three years.
- * Beginning at age 30, women should be screened with a Pap test combined with an Human Papilloma Virus (HPV) test every five years as long as the test results are normal.

Cervical Cancer Screening Guidelines (CCS) 2019:

The American Cancer Society: Women should follow these guidelines to help find cervical cancer early.

- * Women over age 65 who have had regular screening in the past 10 years with normal results can stop cervical cancer screening, after consultation with their gynecologist.
- * Women with a history of a serious pre-cancer, should continue to have testing for at least 20 years after that condition was found, even if the testing goes past age 65.



Other CCS Implications:

- * Women who have had a total hysterectomy (removal of the uterus and cervix) can stop screening, unless the hysterectomy was done as a treatment for cervical pre-cancer (or cancer). **Discuss with your gynecologist/physician.**
- * Women who have had a hysterectomy without removal of the cervix should continue cervical cancer screening according to the previous stated guidelines.
- * Women who are at high risk of cervical cancer because of a suppressed immune system may need to be screened more often.
- * Women who have been vaccinated against HPV should follow the guidelines for their age groups.



Additional Information

- * Women of any age should NOT be screened every year by any screening method if their Pap tests have been normal and they do not have HIV infection or other cause for a weakened immune system.
- * Some women believe that they can stop cervical cancer screening once they have stopped having children. This is not true. They should continue to follow American Cancer Society guidelines.
- * The American Cancer Society guidelines for early detection of cervical cancer do not apply to women who have been diagnosed with cervical cancer or cervical pre-cancer. These women should have follow-up testing and cervical cancer screening as recommended by their health care team.

Importance of Screening

- * Cervical cancer was once one of the most common causes of cancer death for American women. The cervical cancer death rate dropped significantly with the increased use of the Pap test for screening. But the death rate has not changed much over the last 10 years
- * Despite the benefits of cervical cancer screening, not all American women get screened. Most cervical cancers are found in women who have never had a Pap test or who have not had one recently. Women without health insurance and women who have recently immigrated are less likely to have cervical cancer screening.



Screening Disparities:

- * Longitudinal studies show that women who experience ID have a lower incidence of receiving cervical cancer screening than women without ID.
- * Reasons for the disparate screening rates for women with disabilities include lack of knowledge or understanding about exams, anxiety or fear, and absence of recommendation by physician.



Historical Context

- * 1927: Buck v. Bell (made sterilization a legal practice for the unfit, including those with intellectual disabilities).
- * 1930s, 40s and 50s: Overcrowding of state institutions, many children placed there. Overcrowding led to many situations of abuse, neglect and exploitation.
- * Mid 1980s: State run institutions begin to close.
- * 1990s-2000s: Home/Community Based Services for those with IDD. Increased community access, more physicians providing care for the population.
- * Now: Widely (**but not unanimously**) accepted that people who experience IDD are seen as needing the same level of medical care as you or I.





Moving Past the Misconceptions:

- * Individuals with IDD don't have sex.
- * Individuals with IDD can't understand what is being explained to them.
- * Cervical cancer screening is not indicated for this population.

Provider Tips for Success in CCS for Persons with IDD

- * Pre-appointment is possible to explain what the exam will entail, look at the equipment to be utilized and familiarize themselves with the medical provider. Pre-appointment is a time to get detailed medical background if not already familiar.
- * Extra time is often necessary to increase the capacity of patients to consent or assent and to decrease barriers. Gynecologic examinations for cervical cancer screenings, for example, are enabled by more preparation, communication, and planning with support from caregivers.
- * Ask that a caregiver, friend or family member who is familiar with the patient accompany them to the screening if indicated. Also, ask for the contact information of the patient's substitute decision maker, if different than the caregiver. With that keep in mind that many times the patient is the decision maker.
- * Accommodations needed at office appointments (i.e. communication, mobility, timing, and duration of appointments). Consider if no preference, booking first in AM, or first after lunch break, to minimize wait times.
- * Be understanding and patient with parents/guardians as their questions and fears arise, they many times have had to fight hard battles on behalf of the individual they support.



Additional Provider Tips

- * All behavior is communication!
- * Listen to caregivers.
- * Ensure access (reduce noise, fluorescent light), if possible. Speak in a calm manner, allow the patient time to respond.
- * Is there a quiet room/available room that can be accessed if the waiting room proves distressing to the patient.
- * When booking appointment, make sure that it's specified in the patient's information that they have an IDD diagnosis. This will allow you to better prepare for the visit. Ask for previous pertinent medical information to be brought to the appointment.



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