

Pap Camp: Expanding Access, Empowering Care

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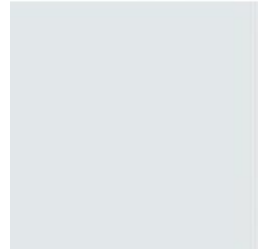


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Provides South Jersey
with its first special
needs primary care
facility with embedded
behavioral health
focused on
care-coordination of
integral services for the
special needs population



We care about you
Coordinate



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Disclosure:

We are thankful for the generosity of the WITH Foundation to fund some of this work



This initiative was funded (or funded in part) by an Inclusive Healthy Communities Grant from the Division of Disability Services, New Jersey Department of Human Services for the development of Pap Camp

And by

HRSA

To improve teaching and access of primary care for people with different abilities



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“ Routine preventative
healthcare isn't an emergency,
it's always an opportunity. ”

- Jennifer M. LeComte, DO, FAAP,
FACP



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Objectives

- Identify barriers to reproductive healthcare examinations
- Identify resources for improving access to reproductive health examinations including “Pap Camp”
- Introduce CARES Manual Resources – Creating Accessible Reproductive Exams and Services



Sexuality

Sexuality is often equated with just ‘physical’ sex. It encompasses gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviors, practices, roles and relationships. It is influenced by psychological, economic, political, social, and biological factors. Sexuality is a natural and healthy aspect of living, and it’s a part of who you are.

‘To be human is to be sexual’ Winder, 1983
<https://sexualityanddisability.org/>



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Position Statement

Every person has the right to exercise choices regarding sexual expression and social relationships. The presence of an intellectual or developmental disability, regardless of severity, does not, in itself, justify loss of rights related to sexuality.



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RISN Opportunity

People with IDD are given few, if any, opportunities to learn about their own reproductive and sexual health.

People with IDD encounter several barriers when accessing routine preventative reproductive care including a lack of provider training and experience.



Lack of Sex Education

- Studies have found that adolescents with ID report low levels of sexual knowledge particularly when compared with their nondisabled (ND) peers.
- For ND individuals, much education about sex-related matters is experiential and gained through informal routes.
- Conversely, young people with ID have fewer friends and spend a large proportion of their time under the supervision of adults. They rely more on their parents or the media for sexual information and express a large number of misunderstandings about sexuality and sexual health.



Lack of Sex Education - Impact

- Lack of sex education makes people with I/DD more vulnerable to unplanned pregnancy and sexually transmitted disease
- Education for people with I/DD should **not** focus exclusively on the dangers, which can cause them to associate sex with "fear-based" avoidance of abuse
- When educated, people with I/DD make informed decisions that are part of the human experience and identify unsafe situations more readily



The Screening Disparity is Severe

- Women with IDD have only 35% cervical cancer screening prevalence and are 70% less likely to receive Pap tests compared to women without disabilities.
- Women with physical disabilities are 48% less likely to receive cervical cancer screening than women without disabilities.
- The disparities are particularly pronounced for women with intellectual and developmental disabilities (IDD)
- This represents one of the most significant healthcare disparities in preventive care



Breast Cancer & Disability

Compared to women without disabilities, women with disabilities have an *equal or greater risk* of having breast cancer.



Patient Level Barriers

- Fear and anxiety about the screening procedure itself
- May call to mind past episodes of abuse or past painful exams
- Lack of knowledge about cervical cancer screening and its importance
- Physical challenges with positioning and tolerating the examination



Supporter Level Barriers

- Misassumptions that women with IDD are not sexually active, leading to perceived low screening necessity
- Fear of finding cancer and having to make difficult treatment decisions
- Lack of support or prioritization of preventive care, particularly for those living with family versus group homes
- Privacy concerns when caregivers must be present during sensitive discussions



Provider Level Barriers

- Lack of awareness of current screening guidelines for patients with disabilities
- Insufficient communication skills to accommodate disability
- Limited knowledge about providing care for patients with disabilities
- Negative attitudes, ableism, and implicit biases that devalue the sexual and reproductive health of women with disabilities
- Erroneous assumptions about sexual inactivity and low HPV risk
- Lack of confidence in providing care to this population
- Time constraints that prevent adequate accommodation



System Level Barriers

- Inaccessible facilities and examination equipment
- Lack of adaptive equipment for positioning
- Lack of representation in educational materials
- Absence of skilled interpreters when needed
- Insurance coverage limitations
- Deprioritization of sexual and reproductive healthcare for women with disabilities




Strategies for Mitigating Barriers: Patient-Centered Approaches

- Provide accessible, easy-to-understand educational materials about cervical cancer screening in advance
- “What Every Woman Should Know”
- Pap Camp
- Allow adequate time for preparation and discussion before the examination
- Consider offering anxiolytics for physically or emotionally challenging examinations



Women's Health and What Every Woman Should Know


Women's Health and What Every Woman Should Know



Prepared by: Rowan Integrated Special Needs (RISN) Center

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In creating this e-zine, we referenced the workbook: *Let's talk about health: What every woman should know* written by Carol Heaton, D.O. prepared by The Arc of New Jersey @ Copyright 1996.



This initiative was funded (or funded in part) by an Inclusive Healthy Communities Grant from the Division of Disability Services, New Jersey Department of Human Services.

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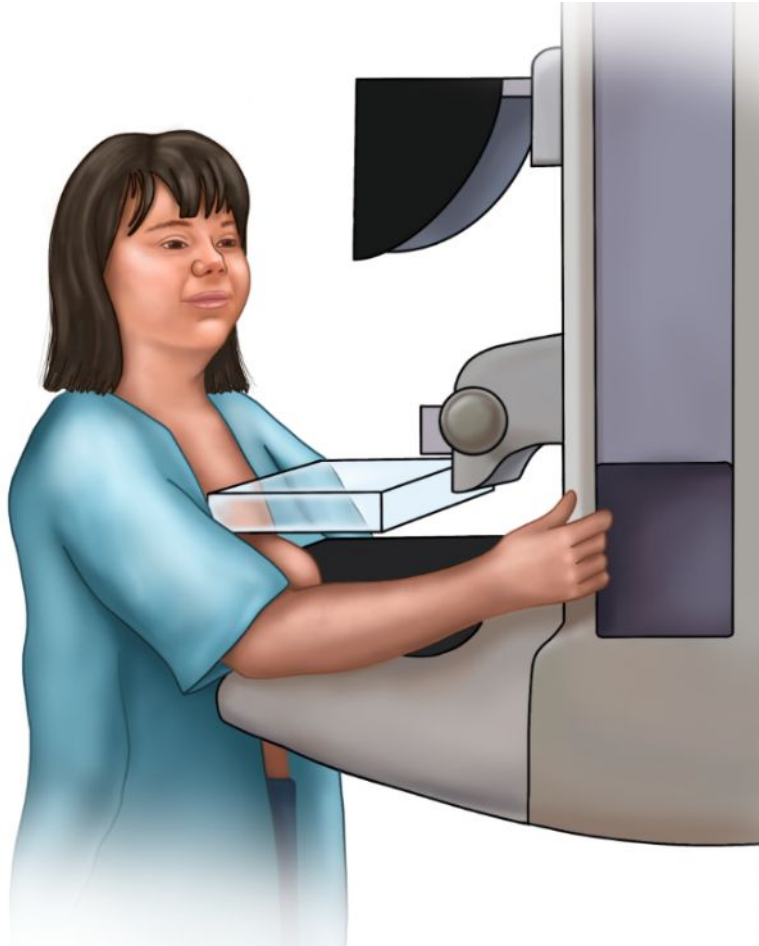
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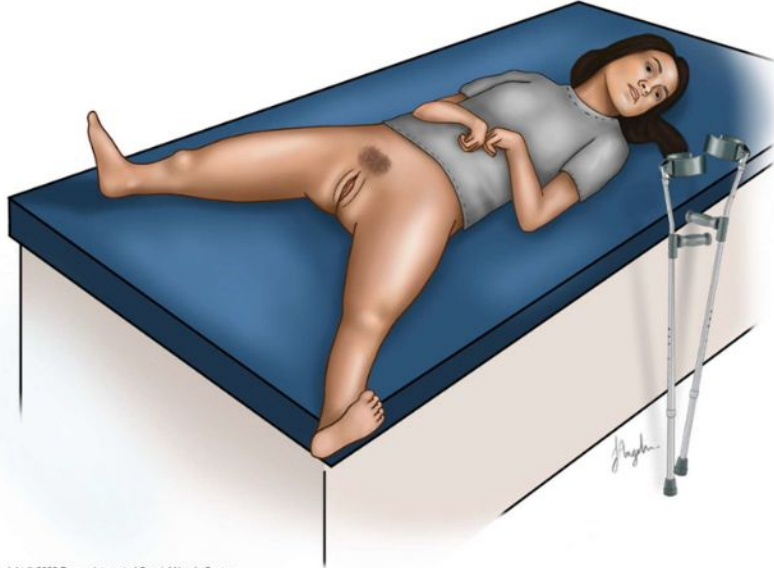
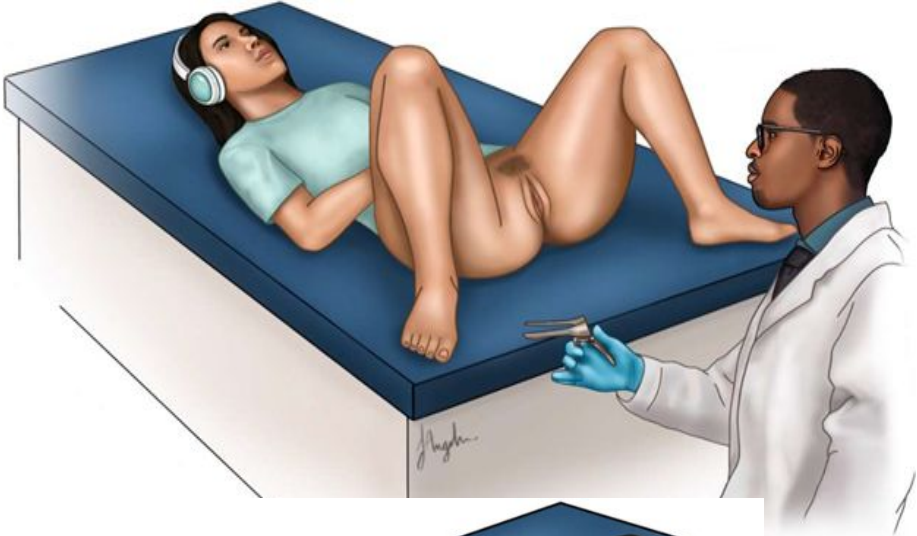
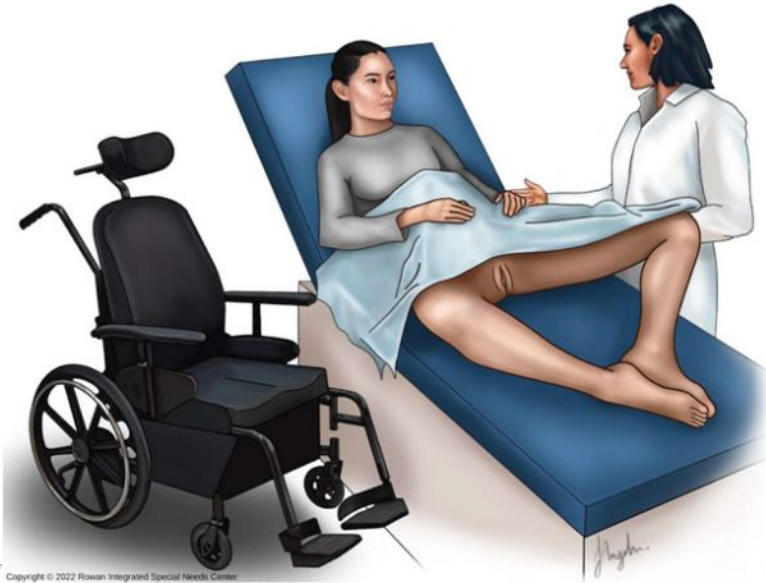
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<https://www.arcnj.org>

Inclusion Matters



Inclusive Illustrations



Pap Camp

- Address knowledge gaps
- Decrease stigma
- Modeling
- Address anxiety and sensory issues
- Increase confidence and self-advocacy





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Pap Camp activity guide

What to
Expect

What to
Know

How to
Prepare



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What is Pap Camp?

At Pap camp, you will learn about

- the exam room
- the pelvic and breast exams
- skills to cope with feelings of stress and anxiety
- permission and consent
- advocating for yourself
- supporting your sensory needs
- developing your care plan
- how to talk to your provider



What to expect

The preventative health exam

Calming your body

Calming your mind

Positive thoughts, distractions

Support

Sensory needs

Plan of care

Activity topics



Feelings check-in

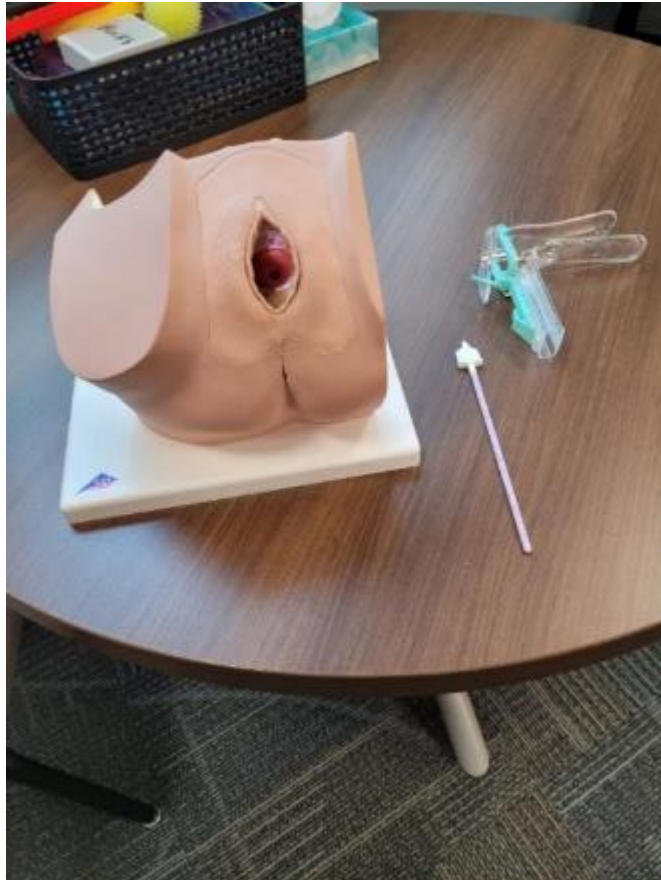
How do you feel about getting the exam?



- Unsure of what will happen
- Scared or anxious about it
- Excited to stay healthy
- Happy to be like everyone else
- Sensitive to sounds, lights, touch, or more
- My feet feel cold in the stirrups
- I've had bad experiences before
- I need help getting on the table
- I like when people tell me what's coming next
- _____
- _____



Pelvic model





Other accommodations

Ask for...

- a longer appointment time
- an interpreter
- an accessible office
- assistance to get onto the exam table
- assistance getting changed or dressed



Plan of care

I will calm my body by:

I will calm my mind by:

My positive thoughts:

Who can support me:

Plan of care

My sensory accommodations:

Other accommodations:

What I will bring to the exam:

Feelings check-in:



Impact of Pap Camp



- Increased knowledge
- Increased confidence
- Increased ability to identify coping mechanisms
- Most would tell a friend
- ACCESS!



Strategies for Mitigating Barriers - Patient-Centered Approaches continued

- Consider offering anxiolytics for physically or emotionally challenging examinations
- In select circumstances, pair screening with other needed procedures or consider sedation when appropriate, with pre-procedure anesthesia consultation
- Explore less invasive HPV testing options before proceeding to speculum examinations when appropriate
- Among women with physical disabilities, 66% believe self-sampling would increase their likelihood of obtaining on-time screening

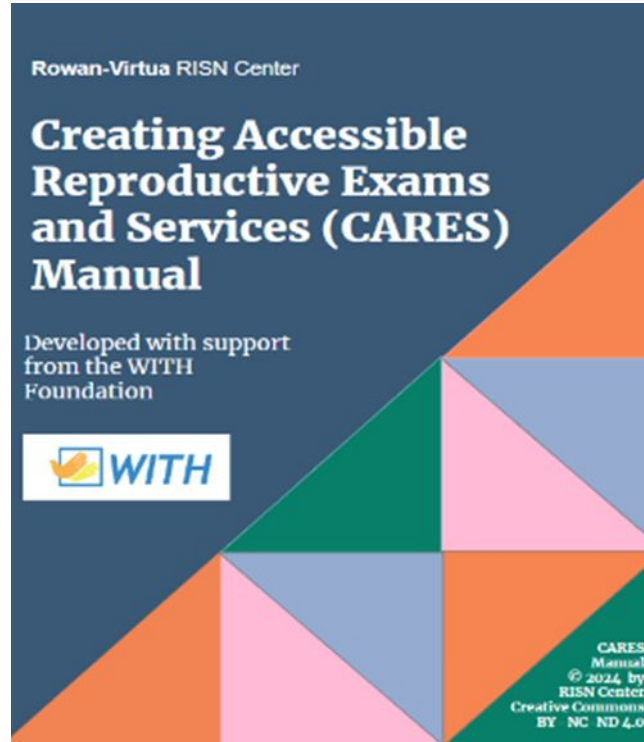


Strategies for Mitigating Barriers - Provider-Centered Approaches

- Increase training and exposure to patients with disabilities during medical education
- Develop communication skills specific to accommodating various disabilities
- Address implicit and explicit biases through education and self-reflection
- Ensure providers understand that capacity to consent should be assumed unless proven otherwise, and recognize that capacity can fluctuate
- CARES Manual



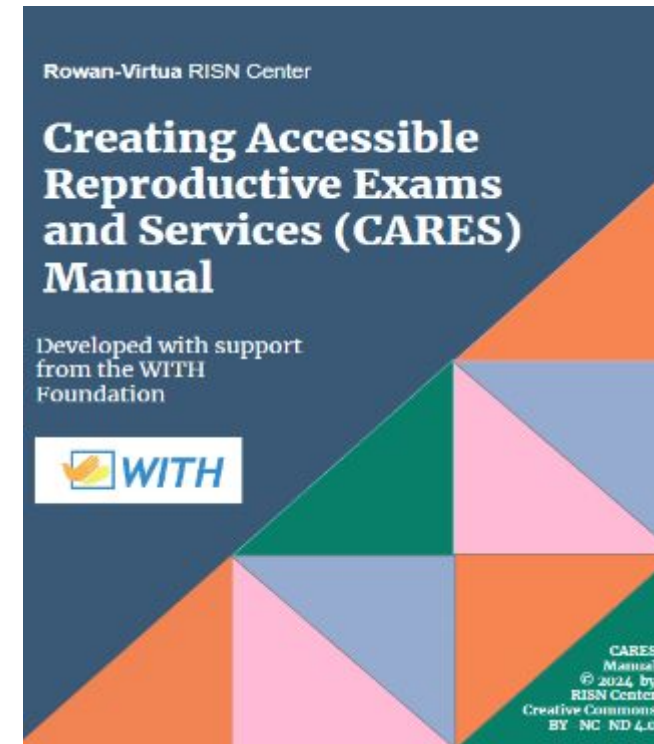
CARES Manual



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CARES Manual Resources – Creating Accessible Reproductive Exams and Services

This manual aims to elevate the standard of care and eliminate healthcare disparities for people with intellectual, developmental and physical disabilities by reducing stigma associated with sexuality education, deescalating patient fears, addressing potential history of medical and sexual trauma, and empowering patients to participate to their fullest extent in their own healthcare decisions.



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CARES Manual Resources – addressing ableism

WHO NEEDS A CERVICAL CANCER SCREENING?



EVERYONE WITH A CERVIX.

Many people believe people with disabilities are not sexually active and therefore, don't need to be screened for cervical cancer.

However, many adults with disabilities **are sexually active**. In fact, one study that polled 100 adults with intellectual disabilities found that **82% of participants have had sexual intercourse**.

Additionally, while sexual activity increases your chance of contracting HPV, **everyone with a cervix is at risk for developing cervical cancer regardless of sexual activity** and should be screened **starting at age 21**.

All people deserve high quality equitable health care.



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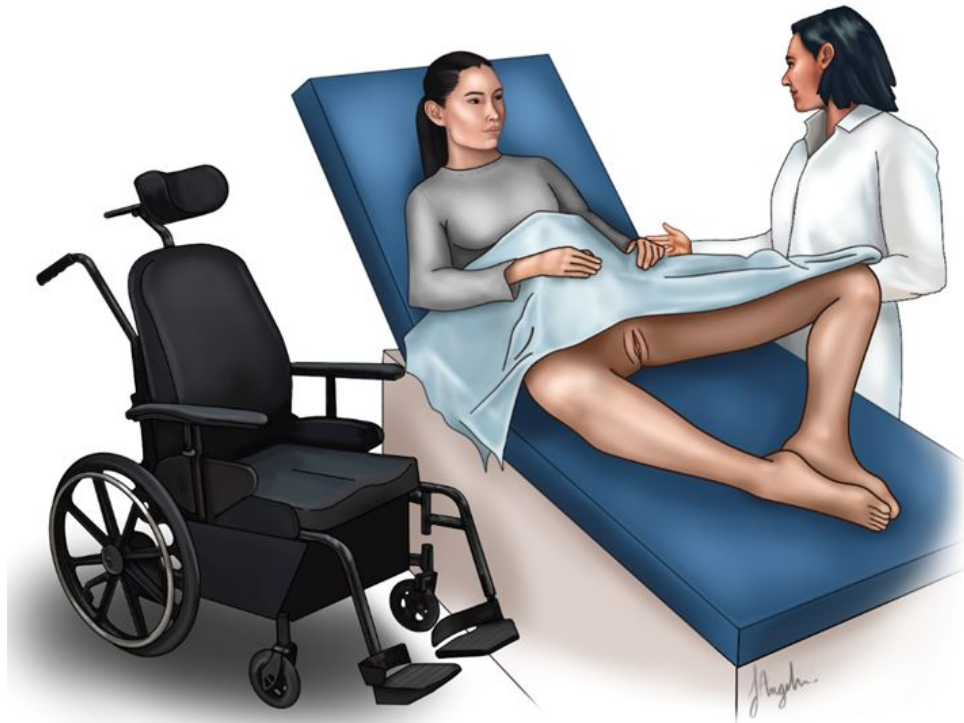
Pap Tests and Pelvic Exams

“My muscles are tight, and my attending interning doctor knew this. He knew about my Cerebral Palsy. I got into the stirrups and tried to get myself in a position where he could examine me. After three or four times of inserting and removing the speculum, he told me that he couldn’t find my cervix. I jokingly said: “Well, I hope I didn’t lose it, doctor, it’s kind of important.” Meanwhile, the entire time this is happening I am clenching my teeth. It HURTS. The attending nurse offers to hold my hand and tells me that everything will be OK, to just relax to make things easier. When he finally finished, he told me that my pelvis was spastic. I wasn’t sure what to take from that. ”



Positions for Exams

We don't think an exam is pleasurable, but it shouldn't hurt either.



CARES Manual Resources – Inclusive Office

HOW TO Create a More Inclusive Office

1 OFFICE ACCOMMODATIONS
Small changes can remove barriers for patients to make them feel more welcome, such as these examples:

- ASK ABOUT ACCOMMODATIONS AT SCHEDULING
- LONGER APPOINTMENT SLOTS
- ACCESSIBLE GENDER INCLUSIVE RESTROOMS

2 INCLUSIVE COMMUNICATION
To ensure each patient receives high quality, equitable health care, consider adding the following accommodations:

- PATIENT-CENTERED LANGUAGE
- ADDRESS PATIENT DIRECTLY
- PRIVATE DOCTOR-PATIENT TIME

3 ADAPTIVE EXAMS
Start discussing exam details prior to the actual exam visit making sure to touch on:

- SENSORY NEEDS & COMFORT
- ADAPTIVE POSITIONS
- STAFF TRAINED FOR TRANSFER/ ASSISTANCE

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CARES Manual Resources – Taking History

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Inclusive History Taking with the 5 P's



1 PERMISSION

Every person is in charge of their body. Give consent before anyone touches your body. Remember that you can say no, even to doctors.

2 PRIVACY

Every person deserves time to speak to their doctor privately. Personal care also requires privacy. You should have privacy if you and a partner engage in physical intimacy.

3 PLEASURE

Every person can experience pleasure differently in their personal life. Having a physical or intellectual disability doesn't change your sexuality but may need more preparation for physical intimacy. Reproductive health exams may require different positions to be comfortable.

4 PROTECTION

Every person should be safe and healthy before being physically intimate. Contraception can help prevent infections, unwanted pregnancy or both.

5 PLANNING PREGNANCY

Every person should discuss family planning with their doctor and partner for a healthy outcome. Chronic conditions may impact a safe pregnancy.

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CARES Manual Resources – Pap Camp

[Self-Advocate Pap Camp Video:](#)

Help prepare your patients with I/DD for their reproductive health exam with...

Pap Camp

This multisensory experience available for patients and caregivers features..

- 
What to Expect During an Exam
- 
How to Advocate for Yourself
- 
Identifying Sensory Needs
- 
Creating a Personal Care Plan
- 

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Abuse Risk

Individuals with I/DD:

- often exhibit nonassertive behavior
- lack the knowledge to differentiate between consensual and nonconsensual sex
- are often socially isolated

The power differential and dependency between a client and a paid caregiver increases the vulnerability to abuse and exploitation!



CARES Manual Resources – Abuse Screen

ABUSE ASSESSMENT SCREEN - DISABILITY (AAS-D)

More than
90% of people with
intellectual disabilities
will experience some form
of abuse at some time in
their lives *



Within the past year,

- 1) Have you been hit, slapped, kicked, pushed, shoved, or otherwise physically hurt by someone?
- 2) Has anyone forced you to have sexual activities?
- 3) Has anyone prevented you from using a wheelchair, cane, respirator, or other assistive devices?
- 4) Has anyone you depend on refused to help you with an important personal need, such as taking your medicine, getting to the bathroom, getting out of bed, bathing, getting dressed, or getting food or drink?
- 5) If you answered yes to any of the questions, who?

*Source: Baladerian, Coleman & Stream (2013); Sotsey & Dae (1991); Boston Globe (2001); Wigham, Taylor & Hilton (2014)



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HITS Survey

The HITS tool is a brief, four-item, validated screening questionnaire used in clinical settings to detect intimate partner violence or domestic abuse

- How often does your partner physically **Hurt** you?
- How often does your partner **Insult** or talk down to you?
- How often does your partner **Threaten** you with harm?
- How often does your partner **Scream** or curse at you?



CARES Manual Resources – LGBTQ+

Reproductive Healthcare for the Pride Community



Health Screening

- ❖ Pap smears are for everyone with a cervix
- ❖ Mammograms are needed despite top surgery or the use of binders or tape
- ❖ Ask about PREP and self collection for HPV test

Anatomy, Not Identity

Compassionate Care

- ❖ Understand unique needs of LGBTQ+ patients
- ❖ Be mindful of pronouns
- ❖ Address stigma of STI's proactively



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Disability and Pride Communities



- Autistic adults are 8x more likely to identify as asexual or “other”
- 57% of autistic women identify as straight; 82% men
- Gender ID vs GAB
 - NT 97%
 - Autistic males 91%
 - Autistic females 78%



[Disability and LGBTQ+ Resource Guide](#)



HPV Self-Sampling Shows Promise

- HPV self-sampling demonstrates comparable accuracy to clinician-collected samples (96% relative sensitivity, 100% relative specificity)
- Control over timing, positioning, and privacy at home
- Elimination of transportation barriers and long clinic waits
- Avoidance of physical challenges with positioning on examination tables
- Reduction in exposure to clinician ableism and assumptions about sexual inactivity



Strategies for Systems Change

- ACOG Emphasizes Equal Access and Addressing Bias
- The American College of Obstetricians and Gynecologists states that patients with disabilities should have access to the same healthcare as all patients, including age-appropriate screening tests.
- Healthcare teams must acknowledge their inherent biases and actively facilitate access to recommended screening, while assuming capacity to consent unless proven otherwise



Thank You/ Questions?



Contact us at RISN@rowan.edu



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