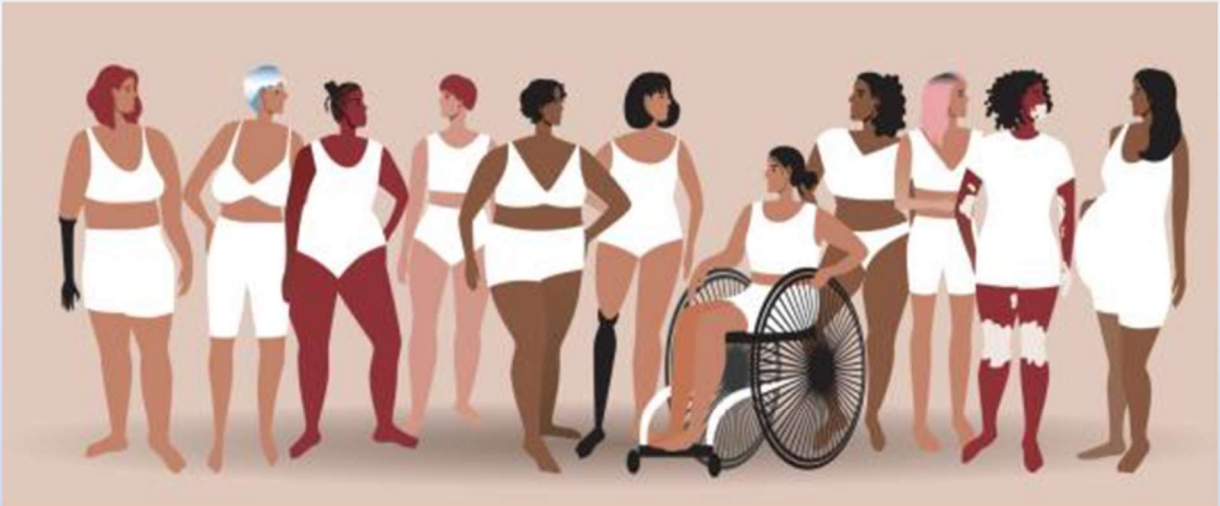


Women's Health and What Every Woman Should Know



Prepared by: Rowan Integrated Special Needs (RISN) Center

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Thank you for your time and support with the creation of this material. Your insight has proved instrumental to increasing awareness of and access to physical, sexual, and reproductive healthcare for women with intellectual and developmental disabilities (IDD).

To our Alliance:

Thank you for your time for advancing inclusion, equity, and advocacy in women's health by contributing your own experience and expectations and engaging your peers in becoming champions of their own health.

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Emily Meale, Sonya Priven, Bhavya Shah, and Kennedy Stafford - thank you for showing us your interest in working with individuals with IDD. The research you performed aided in the development of this educational document.

To the Women Using this Booklet:

We hope you find this booklet helpful in understanding what a women's health exam is and how to get ready for it so you can be your own best advocate and stay healthy. There are some drawings of the exam that will show some private parts. It is important to show this so you know exactly what happens. Anything that is [blue and underlined](#) means that you can click on it to find out more information. Sometimes that will take you to a different page in this booklet and sometimes it will take you to a website on the internet.

Introduction

People with intellectual disabilities and/or developmental disabilities, like all people, have inherent sexual rights. These rights and needs must be affirmed, defended, and respected. - The Arc

[Sexuality Position Statement | The Arc](#)

The Rowan Integrated Special Needs (RISN) Center is dedicated to helping women with disabilities understand their rights to physical, sexual, and reproductive healthcare. All women need to learn about their bodies, how relationships work, about sex, and how to keep themselves safe from disease. We want to teach doctors, healthcare providers, caregivers, and patients about how to get the right care. The information here will help you make your own choices about your health.

Special thanks to our partners:

The Arc of New Jersey and New Jersey Council on Developmental Disabilities



***Disclaimer: The Information on this is for educational purposes only and is not intended to serve as a substitute for a medical, psychiatric, mental health, or behavioral evaluation, diagnosis, or treatment plan by a qualified professional. We recommend you review the educational material with your health providers regarding the specifics of your health care needs. ***

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Making an Appointment

What is Women's Health?

Every woman needs an ongoing relationship with their doctor to maintain excellent health. There are many reasons why you might need a [women's health exam](#). This exam can be done by a special doctor called a gynecologist. Sometimes it can be done by your regular doctor or a nurse practitioner. A women's health exam is part of your overall health. Here is a [checklist of all screenings](#) and exams there are important for your health. Here are some reasons why you might need a women's health exam:

- **You are a woman:**
 - You get your menses (period), and your body changes throughout life especially during puberty and menopause. Your doctor can help you know what changes to expect.
- **Family planning & prevention (birth control):**
 - If you would like to start a family and have a baby, you should discuss with your doctor ways to be healthy before, during and after you get pregnant. If you are sexually active and want to start using birth control, you should call your doctor to make an appointment. There are many different kinds of [birth control](#) options available, so you will want to choose what is best for you.
- **Cancer screening (Pap smear):**
 - When you turn 21, it is recommended that you get your first cervical PAP smear. This can be done at your annual checkup visit, or at a separate appointment. Depending on your age and risk for cervical cancer, this should be done every [3-5 years](#).
- **Breast Health:**
 - A breast exam is very important to screen for breast cancer. This can be done by the doctor at your exam, through a mammogram, and during monthly breast self-exams.
- **Sexual Health:**
 - Sex is something that many adults enjoy and it is important to talk to your doctor about it. Your doctor can help if you have any questions, are having any problems, and make sure you are healthy for sex.
- **Pregnancy care:**
 - Deciding if you want to become pregnant is an important choice. Your doctor can help you plan for pregnancy and make sure you get the care you and your baby need.
- **Something is not right:**
 - If something feels wrong, painful, or different, including pain while urinating (when you pee) or [abnormal bleeding](#) from your vagina, it is a good idea to make an appointment with your provider. If you are not sure, you can still call and ask to speak to someone who may be able to help.



Making an Appointment

- **Finding a doctor:**
 - Your primary care doctor may perform your women's health exam or can help you find a women's health doctor who will be able to meet your needs. You may also ask your family or friends who they like to take care of their women's health needs. The internet can be a good way to find doctors that are close to where you live. [Finding an autism-friendly OB-GYN](#)
- **Do they accept your health insurance?**
 - You can call the doctor's office to see if they accept your insurance. Also, on the back of your insurance card there will be a number to call and ask about providers near you that accept your insurance.
- **Getting to your appointment:**
 - If you need a ride to the doctor's appointment, you can ask your family, caregiver or friend to take you or use public transportation ([AccessLink](#), [Modivcare](#), [Wheelintogo](#), Uber or Lyft)

Resources

- What is a [women's health exam?](#)
- [Checklist of all screenings](#) for a woman to stay healthy
- [Finding an autism-friendly OB-GYN](#)
- Transportation
 - [AccessLink](#)
 - [Modivcare](#)
 - [Wheelintogo](#)
- [Requesting accommodations](#)
- [Medical ID](#) app for your phone
- To bring to your appointment
 - ID card
 - Health insurance card
 - [My Health Care Team and Support Needs](#) worksheet
 - [Health Care Visit Worksheet](#)
 - Your questions for the doctor

Accommodations can make your visit easier

- **Bringing someone to your doctor's appointment:**
 - You might feel worried about seeing the doctor for the first time. You can ask to bring a family member, friend, or aide to the visit. You could also bring a comfort object. You might also ask if staff at the office can assist you with getting changed or getting onto the exam table if you need assistance.
- **Getting into the building:**
 - Check with your provider's office if you have a physical disability to make sure the office is accessible.
- **Asking for an interpreter:**
 - When you make an appointment, let the staff know that you will need an interpreter and what language you need.
- **Thinking about sensory issues:**
 - It might be helpful to let your doctor's office know if any lights, sound or being touched bother you. [Requesting accommodations](#) can be helpful.
- **Planning for your appointment time:**
 - Most appointments take about an hour, but ask your doctor's office to be sure. Choose an appointment for the time of day you are at your best. Ask for additional time if you need it.

What to Discuss with your Provider

We want you to be your own self-advocate. What does this mean? Well, the best person to tell the provider everything about you... is you! You might feel nervous about meeting a new provider or uncomfortable talking about your health, or personal care. How do you remember what to say? Here are some tools that will help you keep track of your questions and important information:

Medical ID App for your phone:



- The [Medical ID](#) app on your phone can help you keep track of your health information. Sit down with someone you trust and fill it out together. When you go to the provider's office, you can use your phone to help you remember your allergies, the medicine you take, and your medical history.

My Health Care Team and Support Needs:

- It can be hard to know who you can go to for help about your questions or problems you are having with your health. The [My Health Care Team and Support Needs](#) worksheet can help you organize and understand the team of people who can best help you.

Today's Health Care Visit:

- [Today's Health Care Visit](#) is a worksheet you can fill out before you see your provider. It helps you plan what you need to talk about with your provider so you do not forget any questions or worries you have. This worksheet also helps you plan for your appointment and remember what your provider tells you.

Both of these worksheets are available on the internet and on the next few pages.



Here are some of the things your provider will want to ask you. It is helpful to think about these topics before your appointment so you can be ready to answer your provider's questions.

- **Why do you need to see the provider today?**
 - Why did you make an appointment? Is it just a check-up, or is something wrong? Your provider will want to ask you for information about any problems or worries you have.
- **Medical History:** This is where you tell your provider all about your health! A lot of this information you already have saved in your Medical ID app on your phone.

Things your provider may ask include:

- **Chronic Medical Conditions:** Why do you see doctors? You may have been born with a genetic condition like Down Syndrome or Fragile X. You may have developed conditions like diabetes, high blood pressure, seizures or thyroid problems. You may have mood problems.
- **Allergies:** Allergies are an abnormal immune system reaction happen to things around us like foods, animals, dust, pollen, and medicine. Are you allergic to anything? Tell your provider if you have any allergies.
- **Medications:** Are you taking any medications? Your provider will want to know the name of the medicine, the dose or (how much), and how often you take each of your medicines. Don't forget to tell your provider if you take vitamins, use eye drops, or use any ointments.
- **Surgery:** Have you ever had surgery or an operation? What was the surgery for? When did it happen?
- **Pap smear:** A pap smear is a test you get at the provider's office to check for cervical cancer. Have you ever gotten a pap smear? When was your last one? What was the result?
- **Sexually Transmitted Infections (STIs):** If you have ever had sex, it is a good idea to get checked for STIs. Your provider can check to make sure you are healthy for sex and didn't get an infection from the person you had sex with. Have you ever had an STI before? Let your provider know what it was, when it happened, and what your provider did to treat the STI.
- **Family History:** Your provider needs to know a little bit about the [health of your family](#). This information about family medical problems helps your provider look for problems you may have now or when you get older. You can create a [Family Health History](#) with this tool.
- **Menstrual Cycle (Period):** Your provider will want to know about your menstrual cycle or period, like when you first got it, when you had your last period, and how long it usually lasts. If you are not sure what your menstrual cycle or period is, go to the [Hygiene section](#) for more information. These questions are important because they help your provider make sure you are healthy and not having any problems with your body.
- **Menopause:** is when a woman stops getting her period after a certain age.





TODAY'S HEALTH CARE VISIT

COMPLETE BEFORE THE VISIT

My Name: _____

Today's Date: _____

Who is with me today? _____

Current list of my medications, pills, and vitamins
(attach it for the doctor or nurse)

Do I have a plan or card that pays for my medicine?

Yes / No (list) _____

Did I recently go see any other doctor or dentist?

Yes / No (who?) _____

What was the reason? _____

Why am I at the doctor's or clinic today?

(Things like illness, check-up, follow-up from previous visit, need forms filled out, need medication change or refill, etc.)

QUESTIONS I WANT TO ASK TODAY

ANSWERS TO MY QUESTIONS

MY TAKE-AWAY INFORMATION

Were there any Medication or Diet Changes?

YES / NO *If yes:*

Medication Name: _____

I am to take this _____ times per day, at _____

I am to stay on this for _____ days (or specify _____)

Why do I need to take this? _____

Medication Name: _____

I am to take this _____ times per day, at _____

I am to stay on this for _____ days (or specify _____)

Why do I need to take this? _____

Are there medications I don't need to take
anymore, or anything else I should know?

**Information about today's treatment plan,
recommendations, and/or follow-up**

(Things like illness, check-up, follow-up from previous visit, need forms filled out, need medication change or refill, etc.)

medical professional signature

date

staff or provider signature

date





HEALTH TEAM DOCUMENT

UNDERSTANDING MY HEALTH CARE TEAM

My Personal Support Team <i>(Identify your personal supporters and their relationship to you)</i>		Formal Supports <i>(Who are paid people that might be with you and what their role is at the visit)</i>	Who Has Legal Authority <i>(Place a check next to who has legal decision-making authority and identify the person)</i>	
Who:	Relationship:	Paid Staff (PCA, DSP):	I have Legal Decision-Making Authority for My Health Care	
			Power(s) of Attorney:	
			1.	
		Residential/Provider Agency Staff:	2.	
			Guardian:	
			1.	
		Other:	Circle: Plenary (full) or Limited	
			Conservator:	
			1.	

UNDERSTANDING MY SUPPORT NEEDS

Areas of Support for Medical Appointments/Events	What I Do/Need and Who Helps Me	Health Professional's Role In Supporting Me
Understanding what the medical professionals are saying, suggesting, recommending or instructing; helping me know my options, pros and cons	<i>Who do I trust to help me understand and how do I communicate with them?</i>	<i>Writing down instructions, using photos or pictures to explain procedures or directions</i>
Communicating my current situation, my decisions/choices, and responding to or asking questions of medical professionals	<i>Who helps me communicate with the medical professionals (doctor/nurse/care coordinator)?</i>	<i>Repeat my answers back to me; ask me to "teach back" instructions; ask me questions</i>
Following through with my medical choices, decisions, or following doctor/nurse/care coordinator's instructions or treatment plan	<i>Who helps with follow through (reminders, set up medications, checking in with me)?</i>	<i>Send out reminders by mail or text; follow-up appointments;</i>



- **Sexual Activity:** Sex is something that many adults enjoy. Your provider can help if you have any questions, are having any problems, and make sure you are healthy for sex. Some questions your provider might ask include: Do you have sex and how often? Do you have sex with men, women, or both? Do you have one sexual partner or many? Do you use protection and what kind? Is it painful when you have sex? Do you ever bleed after sex? Do you have a history of [abuse](#)?



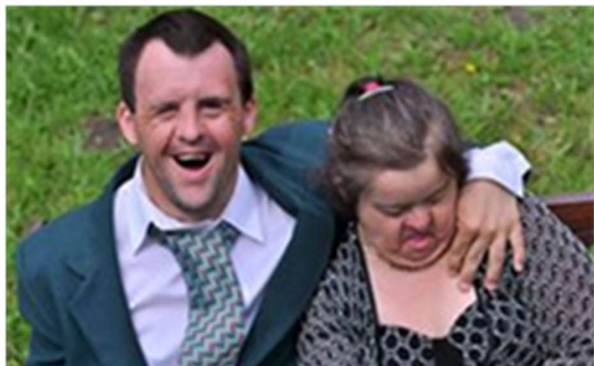
Resources

- [Family Health History Tool](#)
- [Menstruation: What to Expect Video](#)
- [All You Need to Know about Periods Video](#)
- [Menopause booklet](#)
- [Menopause Down Syndrome](#)

- **Pregnancy History:** Deciding if you want to become [pregnant](#) is an important choice. Your provider can help you make a plan for your pregnancy and make sure you get the care you and your baby need. Here are some questions your provider might ask: Have you ever been pregnant? How many times? Have you ever had a miscarriage? A miscarriage is the death of a fetus. A fetus is what a baby is called before it is born. Have you ever had an abortion? An abortion is a medical procedure to end a pregnancy. Do you want to get pregnant or have children?
- **Bladder Health:** The bladder is the part of the body that stores your pee or urine. Another name for going pee is urinate. Sometimes you can have problems urinating (peeing) or get an infection in your bladder. Your provider will want to ask you questions to make sure your bladder is healthy such as: How often do you urinate? Do you ever have trouble urinating? Does it hurt when you urinate? Does your urine smell weird? What color is your urine?
- **Breast Health:** Your provider will want to check to make sure your breasts are healthy and screen for cancer. Sometimes your breasts change or even hurt when you have your period. This is a normal part of having your period. But if your breasts change in other ways or hurt when you don't have your period, you need to talk to your provider. Here are some questions your provider might ask: Have you noticed any changes in the shape or size of your breasts? Do you ever have pain in your breasts? Have you ever felt any lumps in your breasts? Does any fluid come out of your nipple?



“The 5 P’s”: Permission



The 5 P’s stand for Permission, Privacy, Pleasure, Protection and Planning Pregnancy – they are a way of thinking about relationships with romantic partners and other important people in your life, including your doctors and caregivers.

- **Permission** - It is important to remember that your body belongs to you. Taking care of your body includes saying who can touch you and come into your [personal space](#). It is important that we give permission to allow people to touch us and know that we can say NO to anyone, even our doctor, if we do not want to be touched. This is called setting [good boundaries](#).
 - No one can touch your body without your permission. No one can see your body without your permission. Your body should not be shown to anyone who does not want to see it. You decide who touches your body. Some people need help with personal care such as using the bathroom. It is important to remember that everyone should ask permission before they touch you. Everybody deserves to be treated with respect. Your body is private and some parts are more private than others. [Private body parts](#) are parts that are covered by a bathing suit or underwear. Private parts should be covered when you are in public places. If you want to touch your private parts, you should wait until you are in a private place. When you need help with personal care especially when it involves exposing your private areas, you should have privacy. Also, the task is not an act of intimacy, but should be done with your permission. Doctors need to perform physical exams. Doctors and other healthcare professionals should model respect for your privacy during each patient encounter starting with explaining what they are going to do during an exam. They should always ask permission before they examine you and include the use of drapes to maintain your privacy if needed. Even during a doctor's exam, you can say “STOP!” if something doesn’t feel right.
 - Some touches are appropriate, some touches are not appropriate, and some touches are confusing. People with disabilities are more likely to be abused and exploited, that means that they can get hurt by another person. The good news is that talking and teaching about healthy touch and boundaries can keep you safe. You should also respect other people's boundaries. If someone says “NO” when you ask to touch them, like holding hands or giving a hug, you should respect their decision and give them space.

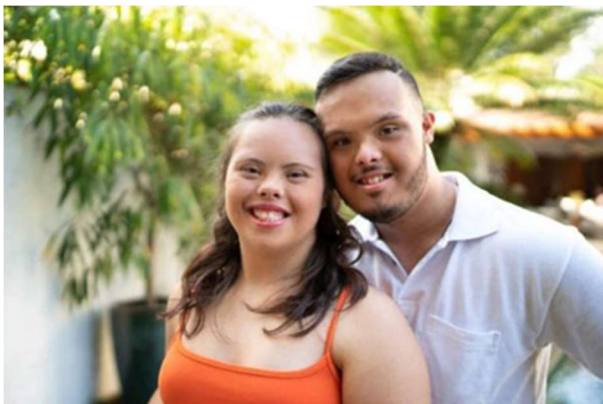
Consent - Another word for permission is Consent. Consent is as easy as FRIES:

- **Freely given.** Consenting is a choice you make without pressure, manipulation, or under the influence of drugs or alcohol.
- **Reversible.** Anyone can change their mind about what they feel like doing, anytime. Even if you've done it before, and even if you're both naked in bed.
- **Informed.** You can only consent to something if you have the full story. For example, if someone says they'll use a condom and then they don't, there isn't full consent.
- **Enthusiastic.** When it comes to sex, you should only do stuff you WANT to do, not things that you feel you're expected to do.
- **Specific.** Saying yes to one thing (like going to the bedroom to make out) doesn't mean you've said yes to others (like having sex).



Supported Decision-Making

- [Supported Decision-Making \(SDM\)](#) allows individuals with disabilities to make choices about their own lives with support from a team of people they choose. Individuals with disabilities choose people they know and trust to be part of a support network to help with decision-making.
- All adults, including individuals with disabilities, have will and preferences, and therefore have the right to make their own decisions, including life decisions about their health care, their finances, their relationships, where they work, where they travel, who they vote for, and where they live and with whom. When you are given the education and are [empowered](#) to make decisions, it has been shown that you can protect yourself in difficult situations.



Resources

Consent

- [Consent: It's Simple as Tea](#)
- [Consent and Communication \(Bear Video\)](#)
- [Consent is Classic](#)
- [Real Talk Consent videos](#)

Supported Decision Making

- [FRAME Video](#)
- [What is SDM?](#)
- [Toolkit](#)
- [NJ age of majority options](#)



Privacy

Everybody deserves to be treated with respect. Your body is private and some parts are more private than others.

- **Private Body Parts:** These are parts that are covered by a bathing suit or underwear. Private parts should be covered when you are in public places. If you want to touch or scratch your private parts you should wait until you are in a private place. Some people with disabilities use attendant services, live in group homes or are dependent on others to help maintain personal care which can lead to intrusion of privacy. It is important that caregivers maintain respect for you and protect your privacy.

Doctors and other healthcare professionals should model respect for your privacy during each patient encounter starting with explaining what they are going to do during an exam.

- They should always ask permission before they examine you and include the use of drapes to maintain your privacy if needed.
- Health care professionals should explain any exam or procedure they need to do that involves touch, make sure you understand and get your permission before proceeding.
- They should stay focused on you, the patient, and finish the exam efficiently so you do not feel uncomfortable; and have the least amount of people in room/least amount of interruptions as possible.
- A chaperone/advocate will be in the room for the private exam - ask for one if not already there!



Zach Anner on [privacy](#)

Resources

Words to Keep You Safe

- [“Secret” vs “surprise”](#)
- [“Confidential”](#)
- [Public vs Private Quiz](#)
- [For Many with Disabilities, Freedom to be Intimate is Rare](#)

Private not secret

- You should never need to keep a secret about touching. You should also never be forced to touch someone else. If you feel uncomfortable about any touch, just say “NO!”. If a touch feels confusing, meaning you don’t feel comfortable or you feel embarrassed about a touch, tell a person you trust.

Confusing Touch

- It feels bad but someone is pressuring you to do it or tells you it feels good
- Someone is touching your private parts and it feels nice but it also feels bad or wrong or against your limits
- You want attention but it feels like the wrong kind of attention or it leads to bad feelings
- You are told to keep it a secret and you are not supposed to keep any touch a secret

In [group home settings](#) there are significant challenges for having privacy to develop intimate relationships. Some of the barriers include sharing rooms, single beds, no locks on doors, may need caregivers to assist in setting up and caregivers aren’t comfortable. Some recommendations for achieving privacy includes using the individualized live plan to assess a couple is in a fully consenting relations before granting full privacy and training staff to establish and maintain a private environment and know how to respond to any challenges or emergencies.

Pleasure

People with a Disability are Often Seen as Not Being Interested in Sex

This is not true. Most people are sexual beings, and have sexual thoughts, attitudes, feelings, desires, and fantasies. Having a physical or intellectual disability doesn't change your sexuality or your desire to express it – or the emotions that can go with it. People with a disability enjoy sex. [There are many myths about sexuality and disability.](#)

People with disabilities also have [diverse sexualities and gender identities](#).

If your disability impairs your physical ability to engage in a regular sex life, or makes you lack confidence, you may feel worried about having sex. Lots of people – with or without disability – have anxiety about sex and sexual performance, and these feelings are completely natural. It takes energy to participate in and enjoy sex, so your disability may get in the way of your sex life to some extent. You may need to talk to your doctor about planning for sex to be sure it is safe for you. Sometimes your chronic conditions require some preparation before sex so that you can experience pleasure. Some preparations include using lubricants, bowel and bladder regimens, and medications to reduce muscle spasms during sex. Some women with spinal cord injuries also need to make sure that they don't experience [autonomic dysfunction](#). Sometimes even after you prepare, you can be nervous or experience pain. You should have an open conversation with your partner to be sure you stop if you are not comfortable.



Planning and positions are not just for sex. You may need to prepare for your women's health exam. Your doctor may need to use different positions so that you don't experience pain or discomfort during your [exam](#).

[Wheelchair Barbie Goes to the Gynecologist:](#) A Perspective on the Sexual and Reproductive Health Care for Women with Disabilities Seminar

Protection

The 4th P stands for Protection – Against Sexually Transmitted Infections and Pregnancy

Contraception Birth control (also called contraception) helps prevent unwanted pregnancy. Your doctor will ask you if you are having sex what type of birth control you are using. Family planning means using birth control. Contraception is a term used to prevent the sperm from reaching the egg, thereby preventing you from getting pregnant. You will be provided with a list of contraceptives here so you can make the best choice along with the help of your doctor. Only condoms prevent [sexually transmitted infections](#) (STIs).

Condoms (Rubbers): The most commonly used and easy to use method of contraception is a condom. A condom can be worn by either the male or the female partner. Condoms serve as a barrier and prevent the sperm from entering the female body. It also prevents transmission of sexually transmitted infections (STI).

Birth control pills (The Pill) are a pack of pills prescribed by the doctor. You take one every day. The packages and pills come in different shapes, sizes, and colors. Most packs of 28 pills. The pills contain hormones that are like the hormones your body already makes. These pills prevent ovulation, which means your ovaries don't release an egg. This prevents pregnancy because there is no egg for sperm to fertilize.

The IUD is a piece of plastic that contains a medication. The IUD is put into the woman's uterus by her doctor and stays there until taken out by the doctor. Doctors think that it stops the egg from sticking to the uterus where a fertilized egg could grow.



Injections and Implants: There are two birth control methods that use a hormone that is like one that a woman's body makes. The hormone is called progesterone. The injection is called Depo-Provera, and the implant is called Nexplanon.

The last kind of contraception is permanent. In females, it is called **tubal ligation** (or “getting your tubes tied”). This is a surgery. The doctor cuts or closes the tubes that connect the ovaries to the uterus so the sperm and egg cannot meet. In males, this surgery is called vasectomy.



Resources

- [Types of Contraceptives](#)
- [How Contraceptives Work](#)
- [What to Know about Birth Control when You Have a Disability](#)
- [How to Use a Condom](#)
- [How Birth Control Pills Work](#)
- [Injections](#)
- [Implant](#)
- [IUD](#)
- [Tubal Ligation](#)

Planning Pregnancy (or not)

The position statement by [The Arc](#) and the American Academy for Intellectual and Developmental Disabilities ([AAIDD](#)) helped define sexuality. It states: ***Individual rights to sexuality are essential to human health and well-being. Without proper planning and education on sexuality, people with intellectual disability can be negatively impacted in gender identity, friendships, self-esteem, body image and awareness, emotional growth, and social behavior.***

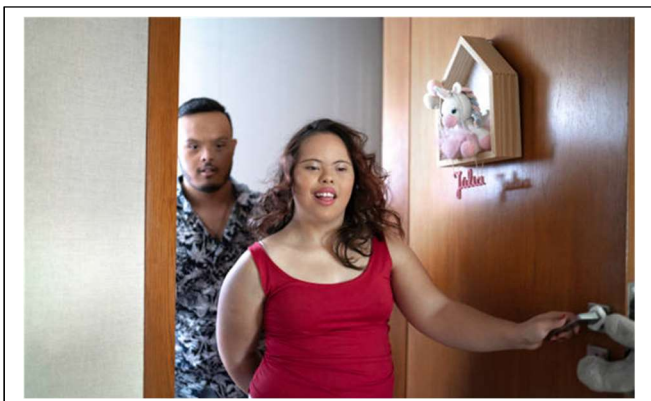
Intimacy is sharing ourselves with another person in a way we would not share with others. Sometimes intimate relationships result in physical affection and sexuality. To have or not to have a child? This is a big decision that you and your partner have to make before having sex. A lack of [sex education](#) makes people with intellectual disability more vulnerable to unplanned pregnancy and sexually transmitted disease. An unplanned [pregnancy](#) can have life changing consequences.

There are many reasons women – both disabled and nondisabled – may find it hard to get pregnant. Some reasons, regardless of disability status, include: being very overweight or underweight, malnourishment, or anemia. Other reasons may be related to your chronic health condition so it is best to deal with genetic testing, medication monitoring and optimizing your health if you are planning to conceive. Your doctor may refer you to a [fertility specialist](#) if you are having trouble getting pregnant. You may also be referred to a maternal-fetal medicine specialist and undergo more monitoring if your pregnancy is high-risk.

Women with physical disabilities encounter significant barriers to accessing maternity care. These barriers include inaccessible health care settings, inaccessible transportation, and clinicians who may not understand the interactions between their disabilities and their pregnancy. Often, social and attitudinal barriers present more of a challenge than physical barriers.

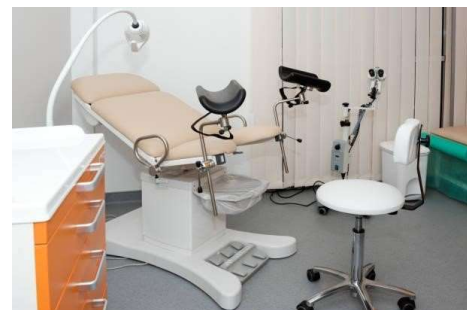
Resources

- [Fast Facts/Advice for Parents with IDD](#)
- [Parenting Tips and Strategies from Parents with Disabilities](#)
- [Parenting with Learning Difficulties](#) Video
- [Caring for a Baby from a Wheelchair](#) video
- [TaLisha twin pregnancy Storytime](#)
- [Pregnancy for Women with CP](#)
- [Giving Birth with CP](#)
- [Access, Autonomy & Dignity: Abortion Care for People with Disabilities](#)

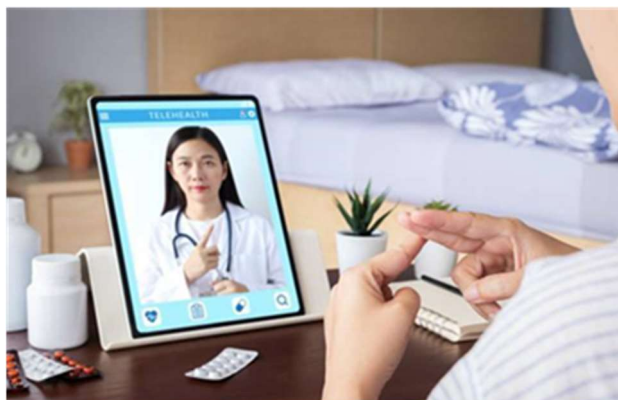


The Exam: An Introduction

- A [women's health exam](#) is important for all women. A women's health exam includes an exam of their breasts and private parts which include the vagina. Many of us feel uncomfortable because we have to show our private parts to the doctor and that's very personal. It's easy to feel scared or embarrassed, but remember that the doctor does this to keep you healthy.
- **Checking in:** When you get to the doctor's office you need to give your name to the receptionist. They will ask about your insurance. Have your insurance and ID cards ready. You may need to sign some forms. Ask questions if you don't understand something.
- **Waiting:** Most of the time you will have to wait to see the doctor. That's because doctors sometimes need more time than they have planned to take care of patients. It's a good idea to take something to read, something to listen to with headphones, or something to look at when you go. It's also a good idea to go with a friend or caregiver you trust to help the time go more quickly. They can also come into the doctor's exam room with you if you want, and can help with answering questions or changing your clothes.
- **When your name is called:** A nurse or nurse assistant will bring you to do some simple tests. You may get on the scale to see how much you weigh. They may take your blood pressure, your temperature and your pulse. They will ask why you are seeing the doctor that day and if you are having any symptoms. You may have to take your clothes off and put on a hospital gown while you wait for the doctor.
- **The doctor will come into the room:** The doctor will come in to start the exam. If you have any questions or worries that you want to talk to the doctor about, ask them right away. The doctor will ask you about your health and health habits. Then he or she will start to look at, listen to, and touch your body. This is called an examination. There are three parts to a women's health examination: the interview, the breast exam, and the pelvic exam.



The Interview



- **The Interview:** The doctor needs to ask [many questions about your health and symptoms](#). They might ask things like: Do you have any new symptoms? Has anything been bothering you? Do you have any allergies? Are you having sex? Are you using any birth control? They also will ask questions about your period. Have your completed [worksheet and phone app](#) ready to help you answer questions.
- **Screening for Abuse:** Many people with disabilities have been abused. Abuse is a word that means to hurt or to harm someone. Physical abuse means hitting or slapping someone. No one should ever do that to another person or to a child. Mental abuse, which is also called emotional abuse, means that another person hurt you by saying or doing mean things or by saying or doing things that makes you feel unloved. Sexual abuse means to hurt you by doing something sexual without your permission. Your doctor may ask you if you have been touched without your permission and if anyone has mistreated you. Talking about sexual violence [video](#)

Remember: Your body belongs to you and you decide who will touch your body. Some touches are appropriate, some touches are inappropriate, and some touches are confusing. If a person touches you in an inappropriate or confusing way, tell the person “NO”, get away and tell a safe person. A safe person is someone who you feel comfortable with and can tell important things. Your doctor is a safe person.

Resources

Sexual Violence Resources

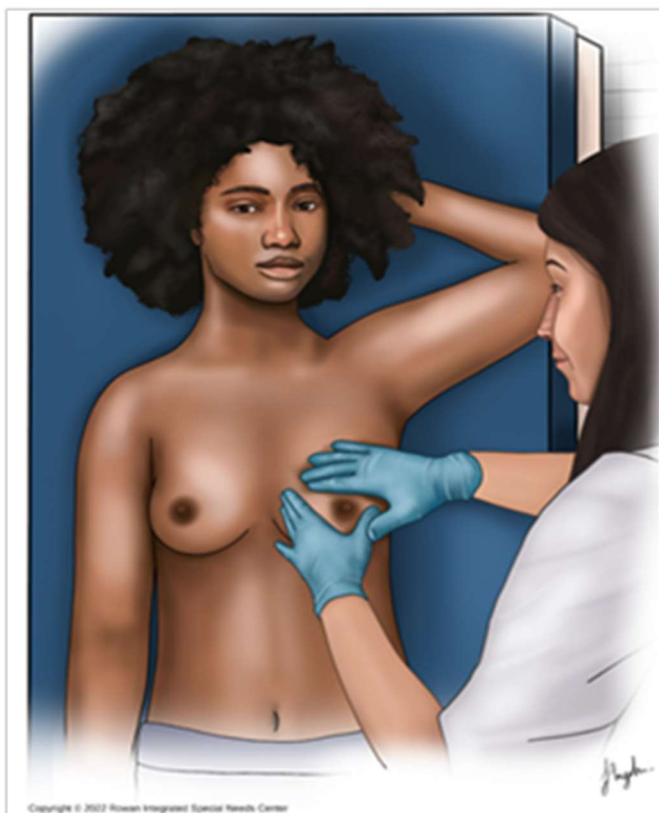
- Talking about sexual violence [video](#)
- [Five things you didn't know about disability and sexual violence](#)
- [On sexual violence](#) from The Arc
- To report suspected abuse DDD hotline **1-800-832-9173**
- [Information](#) on reporting suspected abuse

Physical Examination Resources

- [Clinical Breast Exam](#)
- What is a [pelvic exam](#)?
- [Helpful tips](#) for first exam
- Comic Book - [Tiger Lily - Gyn Princess Warrior](#)
- [Pelvic Exam social story](#)
- [Betty's Story Word and Picture Book](#)
- Video: [Just Checking: Cervical Screening](#)
- Pelvic exam positioning for [cerebral palsy](#)
- What are STI's [sexually transmitted infections](#)
- STI [Video](#)

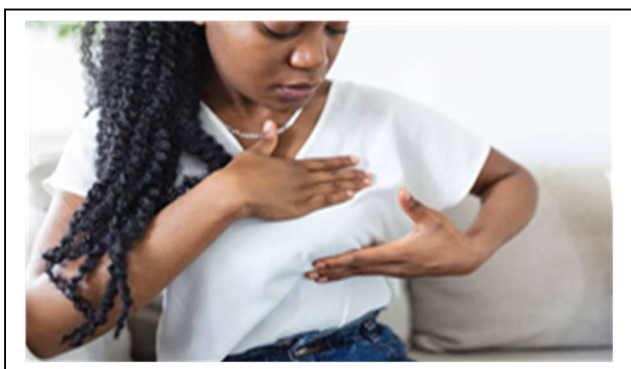
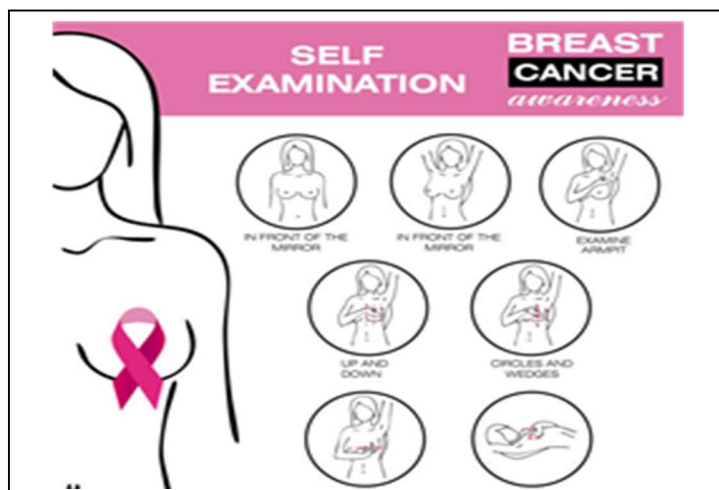
The Breast Exam

A breast exam is very important because it helps the doctor to look for [breast cancer](#). It's a very dangerous disease, women should check themselves every month, and have a doctor check them every year. The doctor will ask you to lay down and will perform a breast examination. During this examination they will ask you to raise each arm, and then will feel each breast and armpit for any abnormal lumps.



What happens during a breast exam

- The [breast exam](#) is an important way of looking for breast cancer.
- You will be given a gown to change into. Wear a bra that is easy to remove. Then you lie back on the examination table. Some providers will put a towel or cloth under your shoulder.
- The provider will then touch your breasts to feel for [lumps or changes](#). Providers may use one or both hands. They may also pull on your nipples to check if fluid comes out. They may have you sit up or lean forward or hold your hands up in the air.
- If you feel uncomfortable at any time do not hesitate to ask the provider what they are doing.
- Your provider can also show you how to do a [breast self-exam](#) at home, which should be done every month.
- Your provider may also recommend a [mammogram](#) depending on your age and symptoms

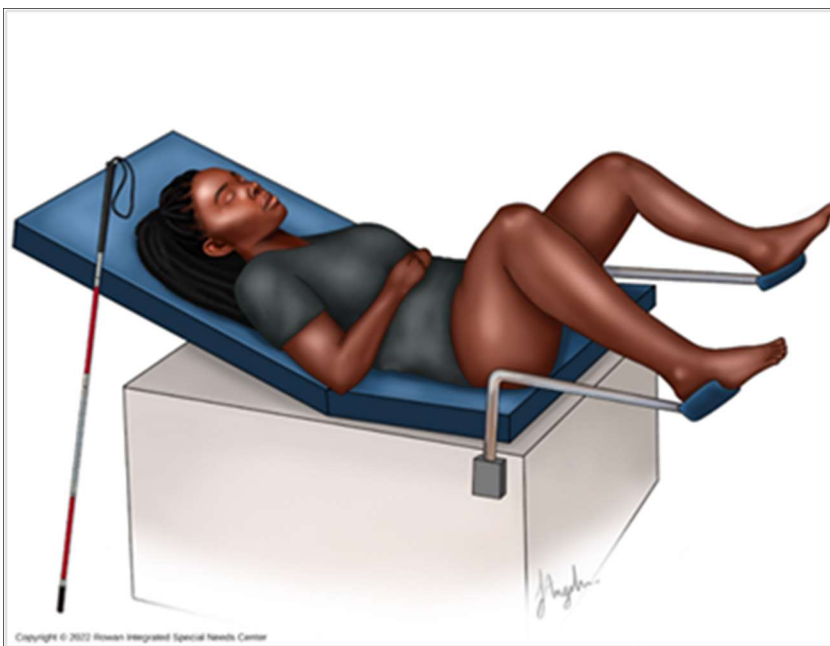
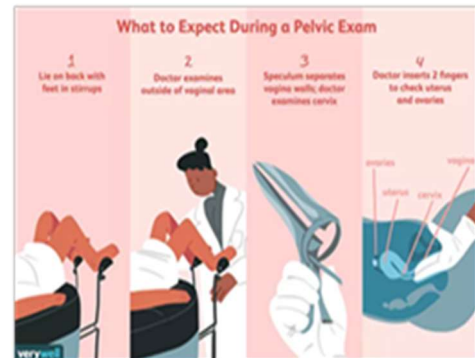


The Pelvic Exam

A [pelvic exam](#) is a physical examination of your pelvic organs. These include your external genitals, such as the vulva, and your internal organs, such as the vagina, cervix, and uterus. A pelvic exam is done by your provider to check for changes to your body. They are also done to be sure you don't have a serious illness like cancer or infections.

- **What Happens During a Pelvic Exam?**

First your provider and nurse will help you get into a special position for the exam. Your provider will have you get on the examination table and lie on your back. If you have trouble lying on your back tell your provider. There are other positions that can be used for your examination. This can be helpful if you have [cerebral palsy](#). Pictures of these other positions are in this chapter.



1) Your provider or nurse will help you get your feet in the stirrups or foot rests.

These are attached to the examination table. You put your feet in the stirrups to hold your legs in the right position.

Let your legs relax and your knees open up. If you can let your knees relax and fall to the side, it will help your provider do the exam quickly and be more comfortable.

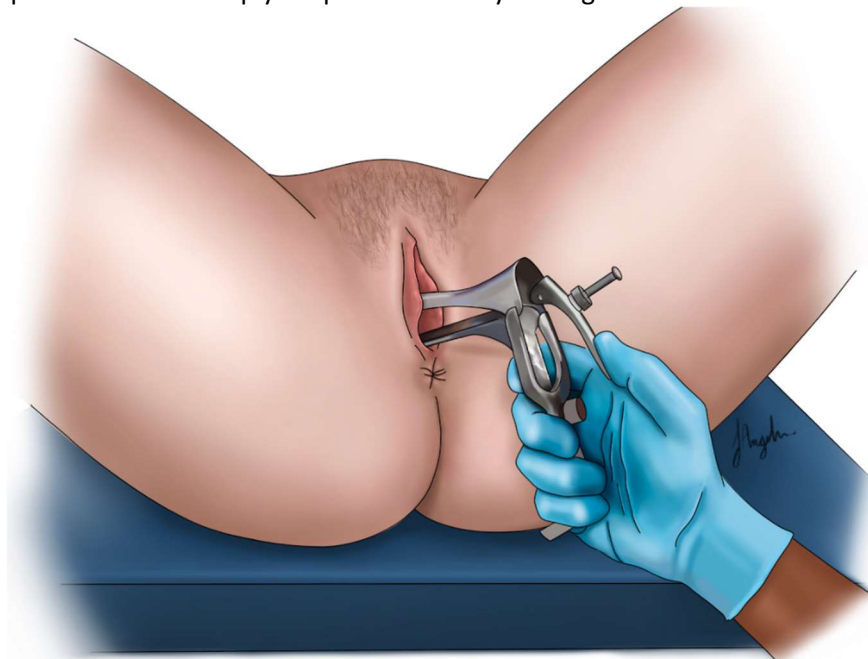
If this position is not comfortable for you, tell your provider.

2) Your provider will look at the external vaginal area for redness, swelling or irritation.



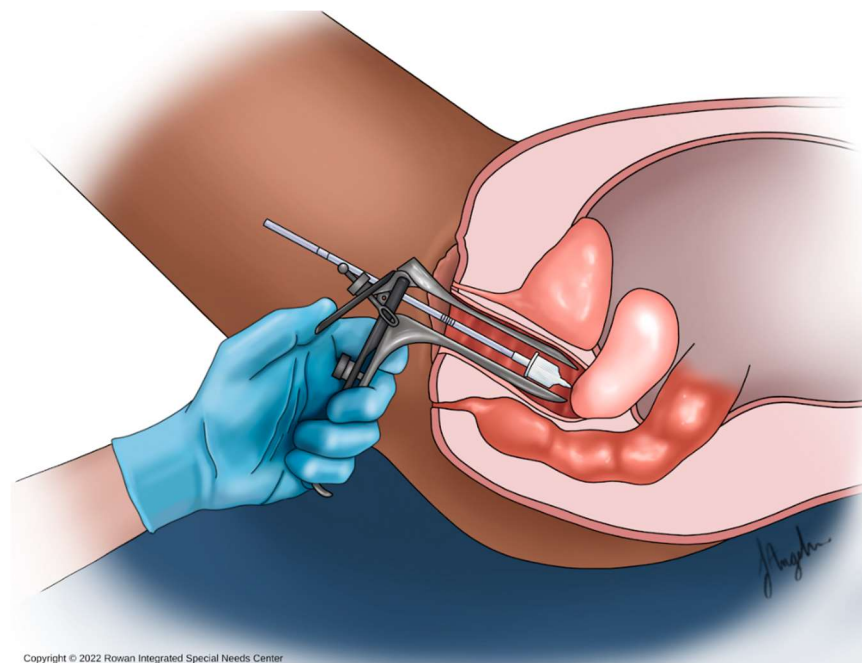
3) Pap Test or Pap Smear:

The Pap test looks for changes in the cells in your cervix that can become cancerous. It is usually done every three years. A speculum is an instrument that is inserted in the vagina to open the vaginal wall. It can be metal or plastic. This will help your provider view your vagina and cervix.



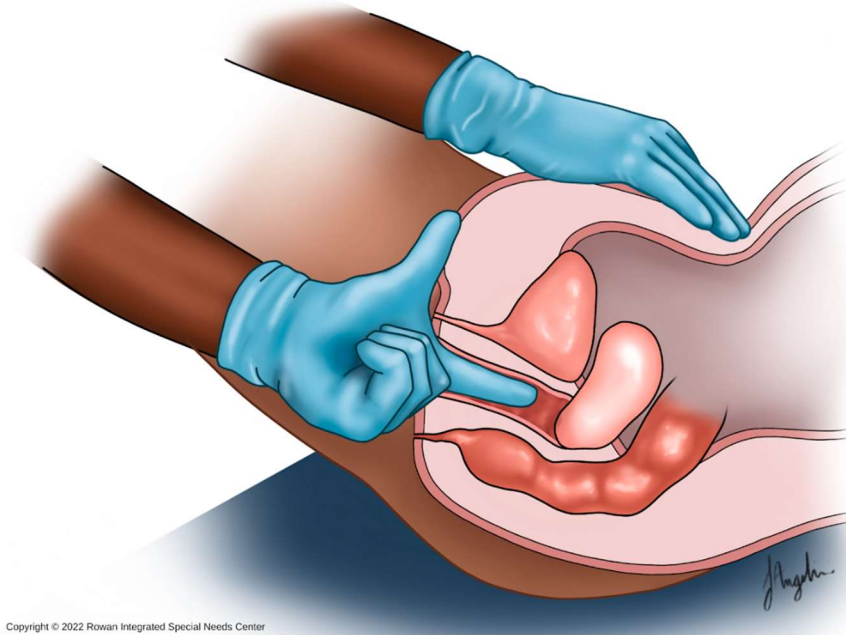
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4) If you are getting a pap test done, a **sample of your cervix tissue** will be taken with another instrument that looks like a brush. It might be a little uncomfortable, but it only lasts a few seconds.



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5) Bimanual exam: [This exam is also part of the pelvic exam.](#) The provider will wear gloves and lubricate two fingers and insert them into your vagina. The provider's other hand will be pressing on your abdomen (belly). They will then compress the tissue between two hands and feel for abnormalities. This exam is important to check the size, and shape of the uterus. It can also help check for fibroid tumors, endometriosis, and ovarian cysts.



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6) Screening for Sexually Transmitted Infections:

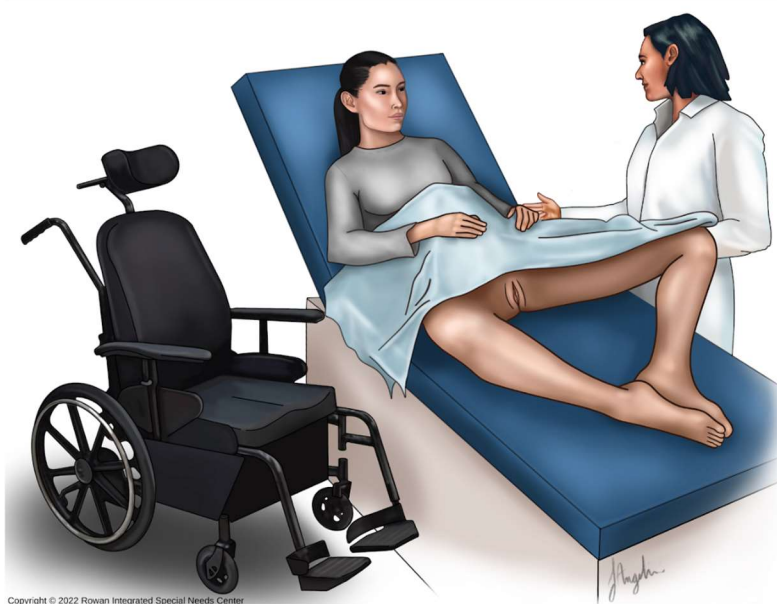
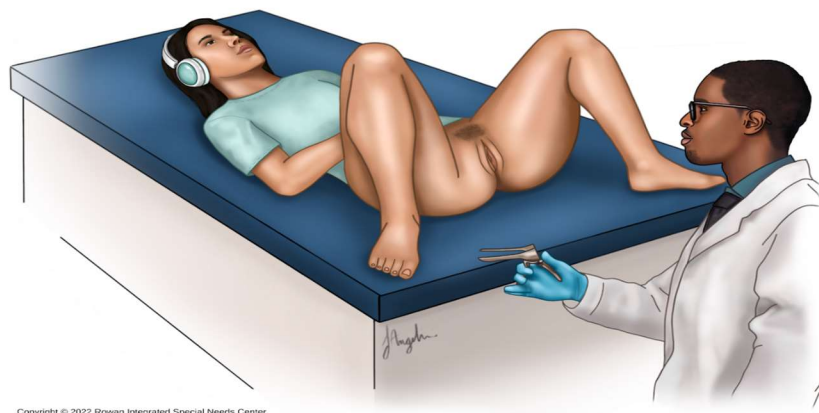
STIs are [sexually transmitted infections](#) that you can get if you have unprotected sex with someone who has the infection. A few examples of STIs are chlamydia, gonorrhea. To check for STI your provider will use a cotton swab to take a sample of your cervical discharge for STI testing. This will be done as part of your pelvic exam when you are laying on the table. You may also be asked to provide a urine sample for screen for STIs.

Some Helpful Tips:

- Dress in comfortable clothes.
- Wear a panty liner in case you have any spotting, a little discharge, or blood after the exam.
- Use relaxation techniques such as deep breathing or distraction. You may want to listen to music or watch a video to distract your mind. You also can bring a partner, family member or friend to talk to during the process.
- Talk to your provider - Let them know if you are nervous and explain how you are feeling. Ask as many questions as you need. Seek advice on how to make the exam easier, such as different positions and using a smaller speculum to ease discomfort or pain. You can ask your provider to talk you through the exam step by step so that you are prepared for what is about to happen.

7) After the exam:

- Test samples from the pap smear are sent to the lab. It will take a few days for your provider to get the results.
- If your results are normal, you will be asked to make a routine follow-up.
- If the results are not normal, your provider will discuss this with you. You should ask your provider how the results will be communicated to you.
- [Further testing](#) may need to be done.

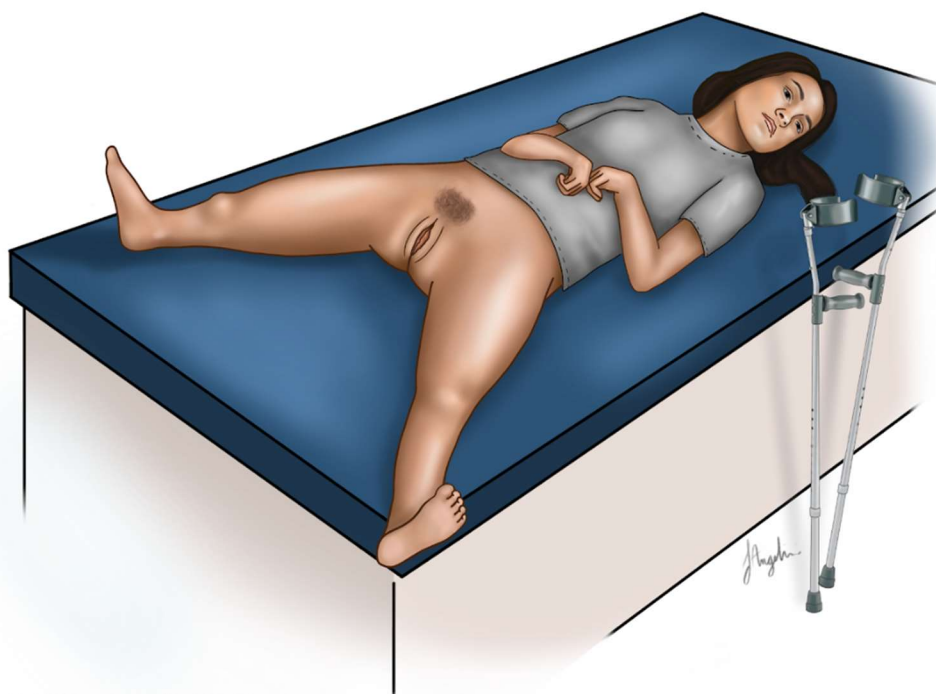
Other positions that can be more comfortable:**Diamond Shape:****M Shaped:**

Knees to Chest:



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V Shaped:



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After the Exam

Congratulations! You have finished your physical exam.

Here are some things to do after your exam once you are home:

- **Schedule your next provider's appointment:**
 - Refer to the [Introduction: Making an Appointment section](#)
- **Pick up your prescriptions:**
 - If your provider prescribed you any medicine, don't forget to pick it up at the pharmacy. Go to the pharmacy and tell the person behind the counter your name and your birthday. They will give you your medicine and tell you how much it costs, or whether it is free because of your insurance.
 - It is very important to follow the directions on your medicine and take it how your doctor wants you to. If you have any side effects from your medicine or if you want to stop taking your medicine for any reason, talk to your doctor first. Your doctor will help you stop your medicine safely and help you find a new medicine if you need it.



- **Watch out for any changes:**
 - It is normal to have some side effects from having a pelvic exam or pap smear. You could feel a little sore or see a little blood or fluid when you wipe after using the bathroom. These should be mild and go away after a day. Call your healthcare provider right away if you have any of the following:
 - Pain in your vaginal area or breasts
 - Cramps
 - Spotting or bleeding from your vagina that is not part of your regular period
 - Know your body including if you have any changes to the shape and feeling of your breasts.

Resources

Breast Self-Exam

- [6-part video series](#) for IDD
- Video [breast self-exam](#)
- Chart [breast self-exam](#)
- [Video](#) for hearing or vision impaired
- [The Right to Know Campaign Breast Cancer Screening](#)

Dexa Scan Videos

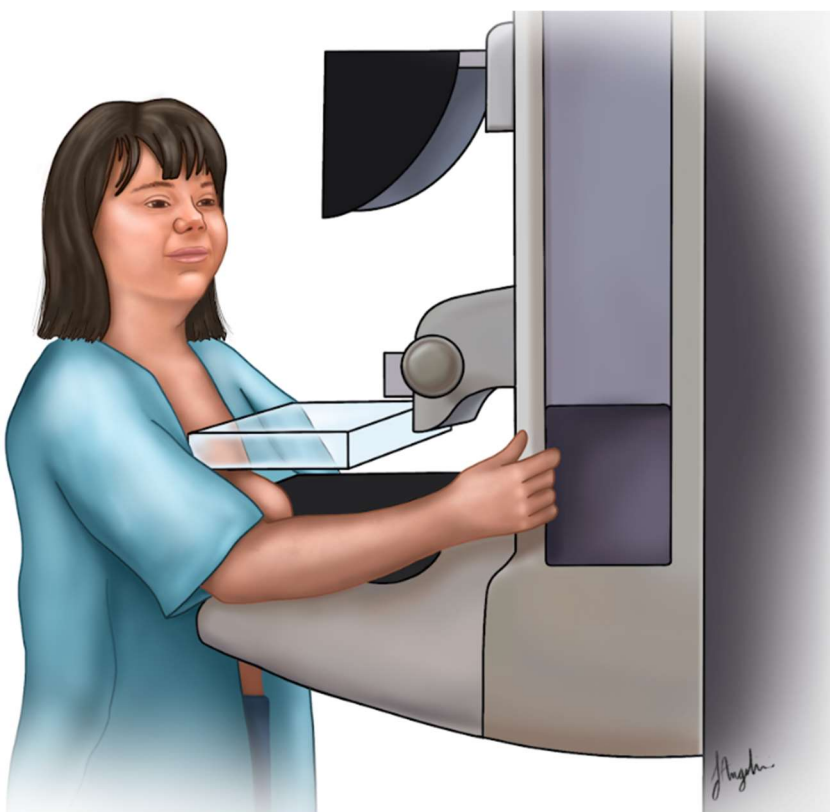
- [How a Dexa Scan Works](#)
- [Video](#) of the exam

Mammogram Resources

- Lisa's Story [Booklet](#)
- Visual [Social Story](#)
- Mammogram [video](#)
- Go For It! [Video](#)
- [Optimizing Mammography services for women with disabilities](#)

Dexa Scan and Mammography

- A **DEXA scan** is a type of X-ray that is used to measure loss of bone. It is used to diagnose osteoporosis. Osteoporosis is when your bones become thinner and weaker. This can often happen after menopause. Most women start getting a DEXA Scan after age 65. Your provider will let you know if you need one sooner.
- A **mammogram** is an X-ray of your breasts. It is a good way to look for signs of breast cancer. If you are over 50 years old, you should be getting a mammogram once a year, but some women start getting them earlier. A mammogram is not done at your regular doctor's office. They are done at special centers that have mammogram machines that can take the X-ray photos. Try to make an appointment just after your period. Your breasts are usually not sore then. Don't wear deodorant or powder on your underarms the day of your visit. If you have a disability that prevents you from standing and/or holding still, you need to tell the person who makes the appointments.

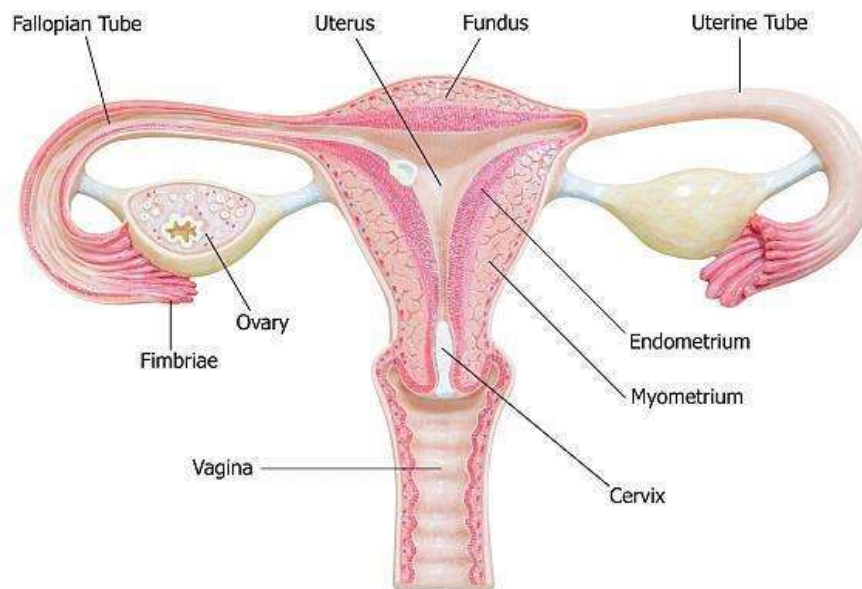


What Happens During a Mammogram?

- The machine takes a picture of your breasts with x-rays.
- The machine has a place where you stand and put your breast in a special position for the x-rays.
- The breast is gently squeezed between flat pieces of plastic. This may feel strange.
- The x-ray technician (the person who takes the x-rays), may pull on your breast to get it in the best spot for the x-ray.
- You have to hold still. If you move, the x-ray gets blurred.

Hygiene

Internal organs: Inside our bodies are many organs that both men and women have. The brain is where we think and remember. The lungs help us get air into our body. The heart pumps blood. The stomach holds the food we have eaten. Women have special organs on the inside. These are the female organs. The ovaries hold an egg, which can grow to be a baby. The fallopian tubes are small tubes between the ovaries in the uterus. A woman's egg goes through the tube to get to the uterus. The uterus is the organ where the baby grows. In most women, it is no bigger than a fist. The vagina is a tube that goes from the bottom of the uterus to the outside of your body.



Menstrual Cycle: When we are teenagers most of us begin menstruation – that means having a period. We have periods because hormones change the inside of the uterus and cause the lining of the uterus to shed. The lining and blood leave your body out your vagina. This process is called your flow. [Here is a short video](#) about periods.



When you see your doctor, you will be asked questions about your period. Keeping a track of the length of your period on your calendar will help your doctor learn more about your sexual health. Some questions the doctor might ask are: Are your periods regular? When was the first day of your last period? How long are your periods? How many days from one period to the next? Do you have any spotting between your periods?

Personal cleanliness:

Women use different products to catch their period blood or flow to stay clean. Examples of products include sanitary pads, tampons, and period underwear. You can set reminders on your phone about changing your tampon or sanitary pad during certain times of the day.

- **Sanitary pads** come in all sizes. The kind of the sanitary pad you use depends on how heavy a flow you have. They can be thin for when you're not bleeding much, and regular or thick for heavier bleeding. You can use whichever size feels most comfortable to you. Stick the pad in your underwear using the sticky strip on the back. Some reusable pads are held in place with snaps or the elastic in your underwear.
- **Tampons** are a very thick piece of cotton shaped like the inside of your vagina. You put the tampon inside your vagina to soak up the blood. Using tampons takes some practice. Some women don't like the feel of putting them in or out but some women think they are more comfortable.
- **Period underwear** is a type of underwear you wear on days when you have your period. You can wash your period underwear in the washing machine, the same way you wash the rest of your underwear. [Thinx](#) and [Knix](#) are some of the most popular brands.
- **Menstrual Cup** is a type of reusable cup that holds the blood from your period. It's a small, flexible funnel-shaped cup made of rubber or silicone that you insert into your vagina to catch and collect period blood.

A period bag is a bag you prepare before you get your period so you are ready when it starts. You can put sanitary pads or tampons, wipes, and a clean pair of underwear in your period bag to carry with you during your period.



Resources

Social Stories about periods

- [Story About Getting My Period](#)
- [Getting My Period](#)
- [How to change pads](#)
- [When to change pads](#)

Videos

- [How to manage periods in a wheelchair](#)
- [Period symptoms and self-care](#)
- [Changing pads](#)
- [How to put a tampon in so it won't hurt](#)
- [Step-by-step putting in a tampon](#)
- [How to use a menstrual cup](#)

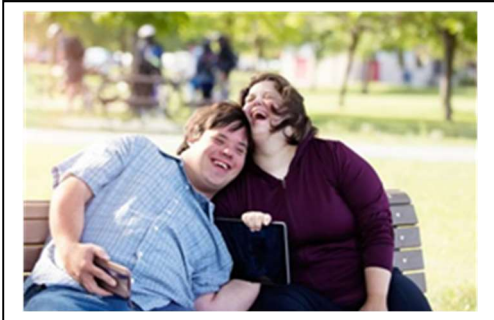
Websites

- [Tampon Insertion Aid for women with disabilities](#)

Toolkit

- [The Healthy Bodies Toolkit for Girls and Boys](#)

Healthy Relationships



All people, including those with intellectual and developmental disabilities, want happy and healthy relationships. These relationships can be friendships, family, or romantic. As we grow up, we all think about sex and sexuality. Sexuality is a word that means different things to different people. We don't have to have sex to be sexual. We can show our feelings in many ways, like holding hands, kissing, hugging, or smiling. Thinking about a romantic or sexual relationship with another person is a big decision that you can make for yourself. A relationship means a special friendship that two people can have, this can also be a

girlfriend-boyfriend, girlfriend-girlfriend, or boyfriend-boyfriend. Questions you have about relationships can be discussed with your family, friends, doctor or others that care about you.

[Real Talk videos](#) show real-life situations and honest conversations from people with disabilities. People of all ages, all genders, all orientations, and all abilities get together and speak openly about everything to do with dating, love, relationships, and sex.

Thinking about your relationship with yourself

- Before you love anyone else, you must love yourself. Thinking about yourself and loving yourself is not selfish. It is called positive self-esteem. Positive self-esteem is when you think about yourself as a person you love and care for very much.

Thinking about relationships with other people

- Relationships mean special friendships that two people can have.
- There are many different kinds of special relationships.
- When we talk about special relationships, we are talking about a romantic relationship

What do I deserve in a relationship?

- It is important to think about what you want in the relationship. You can make a list of all the things you deserve and want for yourself in your relationship

Resources

- [Real Talk Videos](#)
- [Self-care in relationships](#)
- [Our Sexuality, Our Health: A Disabled Advocate's Guide to Relationships, Romance, Sexuality and Sexual Health](#)
- [Love is Love Video](#)
- [Am I Ready for sex?](#)
- [Deciding When You're Ready](#)
- [Videos for Supporters](#)
- [Is That Legal? Online Harassment and Abuse booklet](#)

Love

- You may like someone very much; you wonder if the other person likes you as well. When you like someone very much you wonder if you love that person.
- A person who loves another person never hurts them or forces them to do anything that they don't want to do. You can say no to any type of touch, that is called [consent](#).

Thinking about having sex

- A person whether a woman or a man who has special feelings for someone may start to think about having sex. Often times, people with special needs get negative messages about sex – 'Don't do that, it's not nice!' 'Stop touching yourself, that's bad!'
- It is important to receive information and advice about what sex is. Also, you don't need to have sex when you love someone, and sometimes people have sex without being in love.
- It is important to be careful about having sex. Some of the reasons to be careful is to prevent sexually transmitted infections and having unwanted pregnancy. Check out the [Real Talk Safe Sex videos](#).

Some Basic Rules for Sexual Encounters

- Sex is a voluntary activity! Each person has the right to say yes (consent) or no (deny) to any sexual action. [Consent is important](#). Always respect the decision of your partner and never force them to do something they don't want to do.
- No one should ever force or threaten you to do anything that hurts, makes you uncomfortable, or you simply don't like.
- You can refuse at any point. You might be happy kissing your partner, but don't want them to touch your private body parts. Let them know how far you want to go. Every time is different. Your body and mind probably won't feel the same way in every situation.
- Sex should only happen [in private spaces](#).
- Sexual activities or favors are usually not done in exchange for money or gifts.
- It's important to also [stay safe on the internet](#)

Thinking about getting married

- Marriage is a big part of many people's lives. Many people choose to marry one person and live with that person for the rest of their lives. Many people do not get married. Sometimes it is because the relationship doesn't work out.
- Being single or married has good parts and bad parts.
- It is important to think about things such as:
 - "How would my life change if I got married?"
 - "[Do I want children?](#)"
 - "Do I want to be a parent, or am I ready to be a parent?"



Meet the RISN Center Team



Jennifer M. LeComte, D.O. is a graduate of the Philadelphia College of Osteopathic Medicine. She completed her Med-Peds residency in Delaware at Christiana Care Health System and Nemours A.I. duPont Hospital for Children and is double board certified in Internal Medicine and Pediatrics. She served as a pediatric chief resident at Nemours, as she initiated her career in providing primary care for patients with complex conditions in childhood across the lifespan. She is currently an Associate Professor at RowanSOM in the Internal Medicine and Pediatric departments and is the Medical Director of Rowan Integrated Special Needs (RISN) Center.



Wendy F. Aita, Ph.D. is Co-Director of the RISN Center and Behavioral Health Lead. She is a Clinical Psychologist who received her Ph.D. from Farleigh Dickinson University and completed her internship at Friend's Hospital. She is licensed in New Jersey. She joined Rowan nine years ago and is currently an Assistant Professor at RowanSOM with appointments in both Psychiatry and Psychology. She has worked with individuals, and their families, who are dually-diagnosed with intellectual disability and mental health issues for several years and was the Director of MHID for 2 years. She serves on the Rowan University Neurodiversity Task Force, and she is the Clinical Director for the Strong Minds Program through Special Olympics.



Jennifer Arey, L.S.W. is a Licensed Social Worker for the RISN Center with a degree from Rutgers University and a certificate in Child and Adolescent Well-Being. She works providing individual and family therapy, as well as caregiver support, and has years of experience assisting patients and their care givers with finding resources and accessing needed government programs. Jen serves as the Chair for the Camden County Children's Inter-Agency Coordinating Council's (CIACC) DD-subcommittee, and is on the boards of Camden County Partnership for Children and Say It with Clay.



Mang Yip, L.C.S.W., L.C.A.D.C. graduated from Rutgers University for his BA in Psychology and Stockton University for his Masters in Social Work. Mang has worked in various therapeutic settings including Mobile Response, hospitals, in-home counseling and outpatient community mental health. Mang has worked with children and adults with different level of challenges including trauma, attachment, grief and loss, development, crisis intervention, depression, anxiety, and emotional distress. Mang believes in using evidenced based practice, and empowerment when working with patient and family.