



TAKE CHARGE!

**A Reproductive Health Guide
for Women with Disabilities**

**Presented by
The Empowered Fe Fes**

Acknowledgements

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Judy Panko Reis, Access Living's Health Care Policy Analyst and the former Director of the Women's Clinic at the Rehabilitation Institute of Chicago (RIC) has been crucial in creating this guide. Judy has years of expertise, both professional and personal, in women's reproductive health.

Kennedy Healy, the Women and Girls Intern at Access Living is a student at DePaul University majoring in Women and Gender Studies with a concentration in Disability Studies. Her contributions to this guide stem from her passion for encouraging people with disabilities to claim control of their lives and sexualities. Kennedy has put countless hours into research, writing, and compiling information. Kennedy has been a true asset in completing this project!

We would like to thank Marilyn Martin for her expertise and knowledge of the healthcare system and for her contributions to this guide. Marilyn is Access Living's former Health Care Access Policy Analyst extraordinaire.

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Glossary

Ableism: discrimination or prejudice against individuals with disabilities; denying and withholding resources, agency, and dignity based on ability

Birth Control: the prevention of pregnancy using condoms or medication

Breast Exam: a physical exam of the breast to check for lumps or other changes

Cervix: the lower, narrow end of your uterus that is at the top of your vagina

Gynecologist: a physician who has a successfully completed specialized education and training in the health of the female reproductive system, including the diagnosis and treatment of disorders and diseases

Female Condom: a sheath with a flexible ring at each end that is worn internally by females to prevent pregnancy and lower the risk of Sexually Transmitted Infections (STIs)

Male Condom: a sheath placed over the erect penis before penetration, can prevent pregnancy by blocking the passage of sperm and lowers the risk of Sexually Transmitted Infections (STIs)

Mammogram: an x-ray photograph of the breasts

Pap Smear: a procedure to test for cervical cancer in women that involves collecting cells from your cervix

Pelvic Exam: a relatively short procedure during which your doctor checks your vulva, vagina, cervix, uterus, rectum, pelvis, and ovaries, for masses, growths, or other abnormalities

Reproductive Health: a state of physical, mental, and social well-being in all matters relating to the reproductive system at all stages of life

Reproductive Justice: exists when all people have the social, political, and economic power and resources to make healthy decisions about our gender, bodies, and sexuality for ourselves, our families, and our communities

Reproductive Rights: a series of rights of all couples and individuals to decide freely the number, spacing, and timing of their children and to have the information and means to do so

Reproductive System: the system of organs and parts which function in reproduction including the ovaries, fallopian tubes, uterus, vagina, and vulva

Self-Advocacy: the action of representing oneself, one's views, or one's interests

Sexually Transmitted Infections (STIs): infections that can be transferred from one person to another through sexual contact

Speculum: a medical instrument used to hold open a body passage such as the vagina so that it can be examined

Uterus: a hollow muscular organ in the pelvic area of females, in which the embryo is nourished and develops before birth

Vagina: a tubular passage which is a sex organ that functions for the facilitation of sexual intercourse, childbirth, and menstruation

Vulva: consists of the external genital organs of the female body

FOREWORD

Women with Disabilities Take Charge of Our Healthcare

by Judy Panko Reis

Access Living Healthcare Policy Analyst and former Executive Director,
Rehabilitation Institute of Chicago's Women with Disabilities Center (1993-2010)

If you've ever spent time with The Empowered Fe Fes, a young women's advocacy group at Access Living led by community organizer, Fulani Thrasher, you have surely heard our gleeful shouts celebrating our womanhood and our disabilities. "Disabled, female, and proud" is a slogan popularized by the renowned disabled feminist, Harilyn Rousso. While this spirit drives our advocacy work and unites us in sisterhood, we believe it is also a force that can help empower women with disabilities to take charge of our bodies during encounters with our reproductive healthcare providers. Taking charge is what this guide is all about.

Some might ask why there is a need for reproductive health guide specifically for women with disabilities. Aren't the reproductive health issues the same for women with disabilities as they are for women without disabilities? The answer is a qualified yes. For those of us living with disabilities who use gynecology health services, the clinic or hospital can become a stressful and even scary place when our providers don't understand that we have the same wants and needs as other women. They might focus only on our differences and not on our similarities with other women.

In short, women with disabilities have the same reproductive health needs as other women but may require simple accommodations from their clinicians and staff.

Most barriers that prevent women with disabilities from communicating effectively with their providers can be easily removed by health care staff with the provision of sign language interpreters for women who are deaf and the provision of alternate formats or audio versions of written materials for women who are blind. Providers using simple language and ideas that are easy to grasp enable women with learning and cognitive disabilities to understand the discussions and recommendations their clinicians are sharing with them. Similarly, women living with physical limitations may need staff to help with dressing and undressing and/or getting positioned on an exam table.

This guide will:

- Help you understand your reproductive rights as a woman and your civil rights as a person living with a disability
- Offer suggestions on how to self-advocate to exercise these rights and overcome barriers that could result in denial of your care or in services that are unsafe or of poor quality
- Set forth the results of surveys we conducted with local women's health providers to help you get a sense of how accessible our local healthcare providers are
- Help you understand your right to become a mother with resources for raising children
- Inform you of the resources available if you are experiencing domestic or sexual abuse

Most important, we remind you that you are always entitled to be treated with dignity.

It is not your fault when you are denied care or respect because of your disability. It is our hope that women living with disabilities, family members, providers, and supportive allies will find in this guide suggestions and resources on how we can take charge of reproductive healthcare and wellness to live empowered lives, celebrating with Fulani, the Fe Fes, and me that we are "disabled, female, and proud!"

April 2015

Introduction

The Empowered Fe Fes, a young women's advocacy and peer support group at Access Living sparked the creation of this guidebook. The group gives members a chance to meet other young women with disabilities and lead campaigns around disability and women's rights.

During our meetings we have discussions about disability pride, gender inequality, dating and relationships, self-advocacy, and other topics. Our core values include access, love and respect, empowerment, and building community and awareness. The creation of and contributions to this guide were inspired by the work the Fe Fes do to improve the lives of women with disabilities.

Take Charge! was created for the use of women with disabilities, healthcare providers, parents, and community organizations. Although nearly all sections are geared towards and written to be understood by women with disabilities, others can gain knowledge about reproductive health and disability by reading it. The remaining pages will guide women with disabilities through the steps you can take to keep up with your reproductive health and make important decisions about your body.

For women with disabilities, reproductive "health" is hard to define. In this guide, we do not use the word health in the traditional medical sense. We do not understand health as the absence of disease or the presence of certain abilities.

For us, health means ensuring well being in all aspects of our lives. This includes bodies, minds, relationships, and social environments.

Reproductive health can refer to functions within your body relating to the reproductive system and/or sexuality, such as sexual activity, sexual desires, birth control, sexually transmitted infections, and pregnancy, but the information in this booklet does not end there. We hope this guidebook can be used as a tool to promote overall physical and mental health, while offering specific advice about reproductive and sexual health.

We want this guidebook to be seen as an act of resistance against the harmful ways medicalization has been, and still is, imposed on disabled bodies. Although we are showing readers how to navigate systems that are oppressive to people with disabilities, we are also looking to transform these systems.

By asserting our rights in medical settings, we can help healthcare professionals see that people with disabilities are unbroken, whole, sexual beings who are worthy of lives and dignity. This is just one way to begin making systemic change.

Similar to the ways medicalization has been used to oppress people with disabilities, we recognize that it has also been oppressive to intersex people and people with non-normative gender identities. While the information and language in this guide are geared toward cisgender women with disabilities, we know that taking control of one's body is important for all people. It is our hope that people with other identities might also read this booklet, applying the information within to their lives in ways that make them feel empowered.

This guide was written by a group of women with various disabilities and without disabilities. Because of the different identities of people who contributed, language will vary. The pronouns "we," "us," "they," "them," and "you" will be used to refer to women with disabilities.

AN OVERVIEW

Reproductive Health, Rights, and Justice

DOES REPRODUCTIVE HEALTH IMPACT ME?

Yes! Reproductive health is an important part of your overall health. For some people with disabilities, taking care of all of your health needs can be time consuming and overwhelming. Although it does take time and energy to learn about reproductive health and visit a gynecologist, it is part of making sure all your health-care needs are being met. Healthcare professionals that you visit for concerns related to your disability are not usually trained to take care of your reproductive health needs. These specialists may refer you to other doctors, but may not refer you to a gynecologist because they may see your reproductive system as a part of you that is separate from your disability. Thus, we encourage you to take the initiative to make your own gynecologist appointment, whether or not someone tells you to do so.

I'VE NEVER HEARD OF REPRODUCTIVE HEALTH BEFORE. WHAT'S UP WITH THAT?

People with disabilities are not always given the resources they need to take care of their reproductive health. Society teaches us that sex is a private topic that is impolite or even scandalous to discuss. Schools often assume that people in special education classes do not need sexual education curriculum or cannot attend sexual education courses without interrupting a class of non-disabled people. Doctors, social workers, and other human services professionals help people with disabilities in many facets of our lives, but rarely ask us about our sexual needs. This may be because of the popular assumption that people with disabilities cannot or do not have sex. The Empowered Fe Fes and the Women and Girls Organizer at Access Living, however, are not afraid to talk to you about sex or your reproductive healthcare. We hope you will use us and the other organizations listed in the resource section of this guidebook to learn more about these aspects of your life.

WHAT ARE MY REPRODUCTIVE RIGHTS?

All people, whether they are persons with disabilities or not, have rights when it comes to reproduction and reproductive health. We believe all people should have the right to:

- Seek and receive information about sexuality and reproduction
- Access reproductive health services and contraception
- Choose your intimate partner, marry your intimate partner if you want to, and decide when you want to marry your intimate partner
- Make decisions about your own health, body, sexual life, and identity
- Decide if you want to have children, when you want to have children, how you want to have children, and how many children you want to have
- Decide what type of family to create
- Access family planning, safe and accessible abortion services, and safe and accessible post-abortion care
- Live free from discrimination, coercion and violence, including rape and other sexual violence, forced pregnancy, forced abortion, forced sterilization, and forced marriage

Source: Amnesty International USA

<http://www.amnestyusa.org/ourUwork/issues/womenUsUrights/womenUsUhealthUsexualUandUreproductiveUrights/myUbodyUmyUrights/>

WHAT IS REPRODUCTIVE JUSTICE?

“Reproductive justice exists when all people have the social, political, and economic power and resources to make healthy decisions about our gender, bodies, and sexuality for ourselves, our families, and our communities.”

- FORWARD TOGETHER

Women of color developed reproductive justice in response to the pro-“choice” movement. Reproductive justice recognizes that the choice of having or not having children goes beyond bodies. The race, income level, ability, and other life circumstances of any given person can influence their right to have children and parent them in a healthy environment. Reproductive rights and the pro-choice movement demand that people have control of their bodies. Reproductive justice, on the other hand, demands that people have control of their lives and that the human rights and needs of all people are met.

Neither of these movements has specifically addressed the needs of people with disabilities and their right to have and parent children. However, the reproductive justice movement offers a better framework for us to do this work ourselves. Using the reproductive justice framework, we support the rights of people with disabilities to have and parent children if they choose to do so. We understand that larger systemic change which gives people with disabilities access to more support and economic opportunity is a part of the change that needs to occur in order for this to truly be a choice.

Source: *Forward Together*

<http://forwardtogether.org/assets/docs/ACRJ-RJ-Lens-Toolkit.pdf>



The authors of this guidebook reject the use of disability as rationale for or against abortion. We call out the ableism in pro-choice moments that frame fetuses which may be born with impairments as cases where abortion is obviously necessary. Disability as the rationale for abortion fails to see the complexity of this issue, undermines women's right to make their own decisions, and perpetuates the ableist stereotype that disabled lives are not worth living. At the same time, we reject being framed as people whom pro-life movements are saving. Disability as a reason to deny women rights will not be tolerated. We support educating all people about disability and the ways people with disabilities lead fulfilling lives, but we also understand that these are incredibly complex issues and that abortion is a personal decision.

Keeping up with Your Reproductive Health!

WHERE DO I START?

Taking care of yourself and your reproductive health can seem like a daunting task. Some of this work begins inside of ourselves. We must break down the ableist stereotypes we hear about ourselves and the disability community. We must remember that we are sexual beings, we have the right to be in romantic relationships, get married, and parent children. It is okay for us to have children, even if our impairments are genetic, for more disabled people in the world would not be a bad thing. We are not tragic, we are not pathetic, and we deserve to be loved.

Another beginning step is to make an appointment with a gynecologist if you aren't already seeing one.

A gynecologist is a physician who has successfully completed specialized education and training in the health of the female reproductive system. Gynecologists will have you visit them regularly to check the health of your reproductive system. They will do different screenings and tests that are explained in detail toward the end of this section.

Gynecologists can also help you find options for birth control, do testing for sexually transmitted infections, and treat a range of known issues or problems that involve the female reproductive system. A gynecologist who specializes in obstetrics, more commonly known as an OB-GYN, can provide healthcare before, during, and after pregnancy.

Whether or not you visit a gynecologist, being in touch with your body is important. Paying attention to any changes that may be occurring inside or outside of your body can help you determine if you need to start seeing a gynecologist or other healthcare professional.

For those already seeing gynecologists, paying attention to changes can help your doctor help you. Being in touch with your body may include using a calendar to make sure you are having regular monthly periods, doing breast examinations on yourself (we'll get to that!), or spending time alone getting to know your body.

SELF-ADVOCACY CHECKLIST FOR DOCTOR'S APPOINTMENTS

For women with disabilities, it is very important to know what your needs and wants are and be able to communicate them to healthcare staff. Doctors and other healthcare professionals are often just as uneducated about disability as the general public. For example, they may assume that people with disabilities are incapable of making decisions for themselves or are not sexually active. When we insist on our rights and take control of our healthcare, doctors learn how to better serve our needs. Below are a few steps you can take to advocate for yourself at the doctor.

- ☐ To find a good medical doctor, ask women you trust to refer you to their healthcare providers. Before scheduling an appointment, call first to ask if the doctor has experience with your disability. If you are being referred by another doctor, ask them to find out about a specialist's experience or willingness to treat disabled people before referring you for an appointment.
- ☐ When scheduling an appointment over the phone, remember that not all places are accessible. Be prepared to let the receptionist know any accommodations you might need such as extra time for the appointment, wheelchair access, assistance getting onto/off of the exam table, or a sign language interpreter.
- ☐ Ask about how much services cost and payment options. It is important to know the name of your health insurance(s) if you have insurance.
- ☐ If confronting your physician seems like something that might be difficult for you, try role-playing first with friends or a family member. Practice asserting yourself.
- ☐ Write down your symptoms, questions, medical history, and any medicines or vitamins you are currently taking before your appointment.
- ☐ Arrive at your appointment 15 minutes early for paperwork.
- ☐ You and your doctor need to work as a team for you to get the best care. Doctors might not know everything about your access needs, so be honest about your needs and communicate them to your doctor with confidence.
- ☐ Explain your symptoms and concerns to your doctor.

- ☐ Ask questions about options for treatment and next steps for care.
- ☐ Insist that explanations about treatment be understandable. For example, ask your medical doctor to draw a picture or give you a written explanation that you can understand.
- ☐ Ask for a copy of your medical records and any documents you have signed at the appointment.

Source: "Steps of Self-Advocacy" handout from CWHC; Map to Access
<http://www.proyectovision.net/map/trainers/curriculum/tips.html>

A Self-Advocacy Resource

This is a link to a video that was made by a woman with a disability. She gives examples of how to practice self-advocacy in healthcare settings and work with your doctor to make your healthcare more accessible: **www.proyectovision.net/map/video.html**.

If you need free computer access try your local public library, community college, or use Connect Chicago to find a location near you. Connect Chicago is a loose network of more than 250 places in the city where internet and computer access, digital skills training, and online learning resources are available for free.



Use these Self-Advocacy Phrases!

- "Please slow down."
- "Please repeat what you just said."
- "I don't understand that word."
- "I have more questions."
- "You're not listening to me."
- "Please write down these instructions for me."
- "I would like additional resources and referrals."

How to Partner with Your Doctor

When working with your doctor, remember that you are in charge of your medical care. Think of your healthcare providers as people who work for you.

If you choose to take someone with you to your appointment, make sure your doctor knows that all communication should be directed to you. Be open with your doctor and explain your wants and needs to them with confidence.

Your doctors should be willing to learn from you about your disability, but they may not understand it at first. If you feel that your doctors are not treating you as a capable adult or are being ableist in other ways, you can point their behavior out to them and request that they act differently. Asking them to treat you as they treat non-disabled patients is one way to do this. If your doctor does not change after having this conversation or if you feel frightened or threatened, it's probably best to find a new doctor. What doctor you see is your choice, so you should find doctors that fit your needs best. Any doctor you choose must provide you with appropriate, high-quality care.

Source: Map to Access
<http://www.proyectovision.net/map/trainers/curriculum/tips.html>



Advice from a Fe Fe

BRITTANY RENEE KING is 24 years old and works as a camp counselor at Lincoln Park Cultural Center. In her spare time she likes to watch movies and go to concerts.



Q: Do you have advice for others on how to partner with your doctor?

A: “You would have to talk to your doctor the way you talk to a close friend so you have that comfort and you don’t have to lie. It is not like talking to your parent. Be open and frank about what you’re experiencing.”

Independence and Doctor’s Appointments

Going to the doctor independently may seem difficult or scary but can be beneficial if you feel your parent(s) or guardian(s) limit the conversations you want to have with your doctor. Talking about sex, birth control options, and sexually transmitted infections in front of parents and guardians can be difficult. These are private topics and some parents or guardians do not have sex positive outlooks.

You can decide when you want to start going to the doctor independently. If traveling independently is hard for you, you can ask the person accompanying you to wait in the waiting room.

If you want to talk to your doctor alone or go to your appointment alone but are nervous your parents or guardians will not allow this, have a conversation with them. Explain that you want to start taking charge of your own healthcare and body. Request that they wait in the waiting room, leave the room for part of the appointment, or do not go with you to the appointment at all. Tell them that there are private things you want to discuss with your doctor and that you are capable of doing this independently. Try to remain calm and confident during this discussion.

If you prefer to have someone with you for physical assistance or to help you remember the directions your doctor gives you, know that this person does not have to be your parent or guardian. Find an advocate who supports your independence, allows you make your own decisions, and lets you express your sexuality. For some, this person is a parent or guardian. For others, it is someone else that they trust.

Your Accommodation Rights at the Doctor

by Marilyn Martin

When you receive healthcare services, you have certain rights and protections under U.S. law and The Americans with Disabilities Act. The chart below shows you what accommodations you are entitled to depending on the barriers you face due to your particular disability. Remember to ask for accommodations when you make your appointment so that the doctor's office is prepared for your arrival. You may want to ask that needed accommodations are written into your medical chart.

I cannot get up on the exam table.

You are entitled to be examined lying down on an examination table like other patients. The medical office has two options: it can either make available a height-adjustable exam table to make it possible to transfer from a wheelchair or scooter, or it can make available lifting equipment or a trained lifting team that knows the proper way to transfer a person.

You are NOT required to bring someone to lift you. If it takes time for you to be transferred to the table, then you are required to be given a longer-than-usual appointment. The medical office must also provide stabilizing aids when needed such as pillows and cushions to help prop you up and keep you safe on the exam table.

I am not able to undress myself.

Since you are entitled to the same kind of exam a nondisabled person would be provided, the medical staff must provide assistance in undressing and dressing, as needed. You are NOT required to bring someone to assist you.

I cannot get weighed.

A physical exam is not complete without being weighed. Weight gain and weight loss may be significant symptoms of an illness, and medication dosage is not accurate unless it's based upon your weight. The clinic must make available a weight-accessible scale or refer you for a free weight determination at another clinic that does have such a scale.

I am deaf and cannot hear the staff.

You are entitled to be provided an ASL interpreter. You are NOT required to bring an interpreter with you. Call ahead and explain that you will need an interpreter so the doctor's office can do the needed scheduling. You are NOT required to pay for the interpreter's services.

I am blind and cannot see written material.

You may request that the doctor provide any written materials, including medical directions and instructions, in Braille. Machines that translate materials into Braille are available for purchase, or the doctor can call the American Federation for the Blind if a Braille machine needs to be found.

I am blind, and the staff gives me verbal instructions in the waiting room.

The law entitles you to privacy regarding personal medical information. The medical staff need to communicate with you in a private room and not in front of other patients or staff.

I have a mobility disability, and I cannot use a regular mammogram machine.

Accessible mammography machines do exist. If the doctor's office does not have one, the office is required to refer you to a different facility that does have it.

My disability makes it difficult for me to speak clearly.

The doctor's office must allow you sufficient time to express yourself or to spell out a message on a word board. Let the office know ahead of time that you may need a longer appointment.

My disability requires that I use a service animal, but my doctor's office says animals are not allowed.

As a general rule, a healthcare provider must permit the use of a service animal by an individual with a disability. However, service animals may be kept out of certain areas, such as operating rooms, when their presence would result in a safety hazard. In areas where service dogs are not permitted, staff are responsible for ensuring access continues.

If you believe that your rights to accommodations have been violated, you can call an ADA Specialist. **The Department of Justice operates a toll-free ADA Information Line. Please give them a call Monday, Wednesday, and Friday between 8:30 a.m. and 4:30 p.m. or Thursday between 11:30 a.m. and 4:30 p.m. at 800-514-0301 (voice) or 800-514-0383 (TTY).** All calls are confidential.

There is also a regional Office for Civil Rights that serves Chicago. Contact information for that office is:

Art Garcia, (Acting) Regional Manager
Office for Civil Rights
U.S. Department of Health and Human Services
233 North Michigan Avenue, Suite 240
Chicago, Illinois 60601
Voice Phone (800) 368-1019
Fax: (312) 886-1807
TDD: (800) 537-7697

The Empowered FeFes perform a piece from their "Believe Your Beauty" dance series. This is a project they did in 2012 that is featured in this guide here and on page 44.



Your First Gynecologist Visit

Gynecological exams are checkups for our reproductive system, just like the yearly checkups you may get for your whole body from a family doctor or clinic. You do not have to go to the gynecologist if you are very young, are not sexually active (having genital sex), are not having any issues when it comes to your period, or do not have any kind of pelvic or vulvar pain or discomfort. Nonetheless, just having a consultation, an appointment where you and the doctor simply talk, is a great introduction.

Your gynecologist can answer any questions you may have about sex or your period during this appointment and can also give you advice about how regularly you should be seeing a gynecologist.

Your doctor should base their practices off of your individual needs, especially when working with women with disabilities, as we have diverse needs. Thus, the sooner you can get started with a gynecologist the better. This will allow extra time for you and your doctor to figure out what works best for you.



It is a good time to see a gynecologist if:

- You have fairly regular periods
- You are sexually active or have been sexually active before
- You have a reproductive health concern, question, or issue

THINGS TO EXPECT AT YOUR GYNECOLOGIST APPOINTMENT:

- Some questions about your medical history
- A basic physical exam, just like at a "regular" doctor, including an examination of your eyes, ears, heart, lungs, blood pressure, and weight
- A basic abdominal exam, where the doctor massages your stomach and hip area and will ask if any spots are tender or painful
- The doctor may also take some blood samples from your arm to check your hormone levels (which in the case of abnormal periods, may be out of whack).
- You may also get a standard blood and urine screen for STIs, particularly if you have been sexually active. If you have been sexually active, you should be sure to ask specifically for those tests as some doctors only do them when patients ask for them.
- At some point, you'll be given a gown to get into if you're going to get a pelvic and/or vaginal exam. Most likely, before the pelvic exam, the doctor will do a breast exam, during which the doctor will feel your breasts and chest area in massaging movements to check for any lumps or irregularities. The following section has more information about these screenings and tests.

What are Screenings and Tests?

Screenings and tests are nothing to be afraid of. This is a doctor's way of examining you for a particular reason, and letting you know how your reproductive health is doing.

Some tests are a little strange at first, but they all serve a purpose. Don't be afraid of any test, but also don't be afraid to ask your doctor what the test will feel like if you are nervous. Some tests are supposed to occur multiple times a year, while other tests only occur once every few years. The individual tests and details are broken down below.

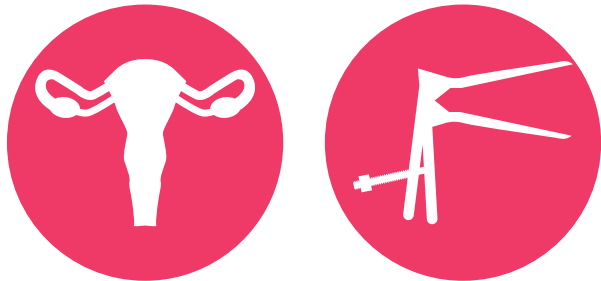
Vaginal Exams

Some people get nervous when they hear the phrase "vaginal exam." But a vaginal exam is simply an exam for a doctor to look at your pelvic region to see if anything out of the ordinary might be occurring.

Your pelvic region has a lot to it. This region of your body includes your vulva, vagina, uterus, cervix, fallopian tubes, ovaries, bladder, and rectum. It's an important exam because it checks the health of many of your important reproductive organs.

Your doctor will check all these organs during the exam. You will have to undress and lie down on an examination table. The doctor will press down on different areas of your abdomen to feel your organs. The doctor may also put two fingers into your vagina to check the size and shape of your organs.

You should start having vaginal exams once you start menstruating or once you start having sex, whichever happens first. You should have a vaginal exam done every year. You can ask your doctor if they will send annual reminders about exams like these.



Pap Smears

A Pap smear is part of the vaginal exam that a doctor performs to check you for cervical cancer. The test determines the health of your cervix (the opening to your uterus). When and how often you get tested changes depending on your age and other tests you have received. Right now, it is best to follow these basic guidelines:

- Once you turn 21, you should have a Pap smear once every three years.
- Women ages 30 to 65 should receive a Pap smear and Human papillomavirus (HPV) test every five years. This is called co-testing. Because HPV is the most commonly sexually transmitted disease in the United States, it is recommended that you have both tests. If your HPV test comes back negative, then you should continue with a Pap screening every five years until age 65 when testing ends.
- If you are a woman between ages 30 and 65 who is only having Pap smears and is not being tested for HPV, the Pap test should continue every three years.

Important Note:

If you received an HPV vaccination you still require cervical cancer (Pap) screenings. If you have the HPV vaccine the same guidelines apply to those who haven't received the vaccination.

Pap guidelines change often. If you still are not sure when to get tested, please ask your doctor for more information.

The test does not require a lot physically. It might be scary the first time you have one, but don't worry! The exam might cause a little discomfort, but it should not hurt. Feel free to ask your doctor any questions or worries you might have during your exam.

You will have to lie on an examination table and have your feet positioned in stirrups so the doctor can examine your vagina. A doctor places a metal tool called a speculum into the vagina for your examination. The doctor then takes some cells from your cervix, which a lab analyzes to check for cancer. It's a very quick procedure!

Try to remember these important details about the test:

- You can't be on your period when you go in for a Pap smear.
- You shouldn't have sex 24 hours before or after your Pap smear.
- You shouldn't take a bath 24 hours before your Pap smear. But showers are fine!

Mammograms

A mammogram is an x-ray picture of the breast that is used to detect breast cancer. Women ages 40 to 74 get mammograms every two years to screen for breast cancer, which is more common among older women. Younger women may be asked to get a mammogram if they have signs or symptoms that are associated with breast cancer.

A mammogram is taken using a mammography machine. This machine has two plates that your breasts will be compressed or squeezed between. The bottom plate is the plate that will take the picture, while the top plate is adjustable and plastic. Once your breast is placed on the bottom plate, the person taking the x-ray will lower the top plate onto your breast. This compression may cause some discomfort, but it is important for getting a clear picture. If you feel pain, tell the person who is helping you and they may be able to position you so that you are more comfortable.

You will not be in this position for long, as the x-ray should take just seconds. The person assisting you will leave the room to take the picture then remove the top plate. Depending on your situation, you may have to get more than one x-ray of each breast. But don't worry, the process goes quickly!

If you have a mobility disability and cannot stand for a mammogram using a traditional machine, let your doctor know so that you can be referred to a clinic that has an accessible mammogram machine that allows you to remain seated in a wheelchair or scooter.

Breast Exams

Doing self examinations of your breasts is another way to keep up with your reproductive healthcare. Most doctors recommend that you do a self breast examination once a month. Doing these regularly makes it easier for you to realize if any changes are occurring.

If you notice redness, soreness, internal or external lumps, dimpling of the skin, or discharge from your nipples, tell your health-care provider. If you are unable to do a breast exam for yourself, ask your personal care attendant or someone you feel comfortable with to help you. There are three ways to do a breast examination at home.

In the Shower

It can sometimes be easier to detect lumps when your breasts are wet and soapy. Move the pads of your fingers around your breast and armpit in a circular motion to check for lumps.

In Front of a Mirror

Some changes are easier to see than they are to feel. Look for changes in nipple position, dimpling of the skin, redness, or soreness. Squeeze your nipple and make sure there is no discharge (unless, of course, you are lactating, i.e., nursing a baby).

While Lying Down

You should also check your breasts while lying down. Again, move the pads of your fingers in a circular motion over your breast and armpit to check for lumps.



Birth Control and Contraception for Women with Disabilities

by Judy Panko Reis

If you do not want to become pregnant, you may want to consider using birth control that is safe and easy to use with your disability.

This means you will want to work closely with your nurse or provider to discuss a method that works best for you. For example, if you've had a stroke your provider may advise you to avoid oral medicine because it may not be safe for you. Or if you are unable to use your hands, certain forms of birth control might not be easy for you.

It's very important to remember that the choice to use a specific form of birth control is always your choice. Choosing a form of birth control is your right. You should never feel pressured by family members, guardians, or clinicians to use a form of contraception that permanently sterilizes you (prevents you from ever getting your period or getting pregnant) if this is not your choice. You should never feel forced by others to use any method that does not feel comfortable for you.

Before you use a particular birth control method or procedure, it's important for you to ask your provider:

"Why is this method best for me and my disability?"

"What are the side effects or risks of using this method?"

"How do I use this method so that it is effective?"

Sexually Transmitted Infections (STIs)

Sexually Transmitted Infections (STIs) are acquired through sexual contact, semen, vaginal fluids, or other bodily fluids. They can also be acquired through blood transfusions, sharing needles, or during childbirth. Having yourself or your partner tested for STIs is important in assuring there will be no transmission of STIs during sexual activity.

Ask your healthcare provider or gynecologist for more information about STIs if you are considering having sex for the first time or with a new partner. Many people with STIs experience no symptoms at all but can still pass on the infection. Getting tested is the only way of truly knowing your status.

If you are still in high school, there is most likely a health program that gives students information on STIs and sexual health. If you are not being given this information, ask if there is a program you can be a part of. Explain that people with disabilities should not be excluded from these courses because our disabilities do not erase our sexualities.

Many STIs are curable or killable, and all are treatable.

Getting treated for an STI can help prevent more serious health effects. If you think you may have an STI, you should notify your doctor right away. Signs that indicate STIs may include:

- Sores or bumps on the genitals or in the oral or rectal area
- Painful or burning urination
- Unusual or odd-smelling vaginal discharge
- Unusual vaginal bleeding
- Pain during sex
- Sore, swollen lymph nodes, particularly in the groin but sometimes more widespread
- Lower abdominal pain
- Rash over the trunk, hands, or feet

Methods for Preventing Sexually Transmitted Infections (STIs) and Unplanned Pregnancy

There are many different ways to prevent STIs and unplanned pregnancy while being sexually active. Below are some methods that go beyond abstinence or birth control medications (which are also good options if they work for you). For those who wish to be sexually active while preventing unplanned pregnancy or STIs, we recommend using or combining methods for the safest sex.

Female Condom Receptive/Internal (Effective)

Female or receptive/internal condoms prevent bodily fluids from mixing during sexual activity. Each end has a flexible ring to keep the condom in place after it is inserted into the vagina or anus. Female condoms can be inserted up to 8 hours before sexual activity. When used correctly, female condoms will effectively prevent STI transmission and only 5% of users may experience an unplanned pregnancy.

Male Condom Insertive/External (Effective)

Male or insertive/external (outside) condoms prevent bodily fluids from mixing during sexual activity. The condom is put onto the penis or sex toy before it comes into contact with the vagina, mouth, or anus. When used correctly, male condoms will effectively prevent STI transmission and only 2% of users may experience an unplanned pregnancy.

Dental Dams (Effective)

Dental dams are small rectangles of latex or silicone used to prevent infection during oral-vaginal or oral-anal sexual contact. Non-microwavable plastic wrap can be a less expensive substitute for a dental dam. You can also create a dental dam by cutting off the tip of a male or female condom and cutting along the side.

Withdrawal (Less Effective)

Withdrawal is when the penis pulls out of the vagina, anus, or mouth prior to ejaculation. Anyone who uses this method should be aware that pre-ejaculation fluid will still be exchanged and it also carries a risk of STI transmission or pregnancy. This method works best if the partners agree to use it in advance and if there is increased awareness of when ejaculation is about to occur. Approximately 27% of users may experience unplanned pregnancy while using this method.

Rhythm Method Fertility Awareness Method (Less Effective)

The rhythm or fertility awareness method is a way of understanding a person's reproductive and menstrual cycle by observing and writing down fertility signs. Because the body is actually fertile during only about one-fourth of a menstrual cycle, these signs give clues about whether or not someone may become pregnant on a given day. This method is a great way for someone to learn about their body, but it is not recommended as the only form of protection in preventing STIs or pregnancy.

No Method (Not Effective)

Choosing to use no method of protection or prevention is an option, but it is not effective in preventing STIs or unplanned pregnancy.

Sources: Project Ark

<http://projectark.wustl.edu/OutreachPrevention/HIVSTDFacts/tabid/782/Default.aspx>

ICAH Illinois Caucus for Adolescent Health, *Youth Guide to Sexual Health*

Violence and Abuse

by Judy Panko Reis

Domestic violence occurs when (for example, a family member, spouse, partner, friend, service provider or caregiver) repeatedly hurts or harms you physically, emotionally, sexually, or financially.

The abuser uses fear to control you. Women with disabilities are more vulnerable to becoming victims of domestic violence and abuse than other women because offenders may see them as easy targets. Because domestic violence is never the fault of the woman with a disability, responsibility for the abuse always rests with the abuser.

Examples of physical abuse include:

Confining or restraining you, withholding your assistive equipment such as walker, hearing aids, wheelchair, or respirator. Refusing to assist you with activities of daily living such as getting out of bed, bathing, eating etc. Denying you medications or transportation. Physically hitting or harming you.

Examples of emotional abuse include:

Verbal abuse, neglect, abandonment, and denying that you have a disability.

Examples of sexual abuse include:

Demanding sexual favors in return for help. Taking advantage of your disability by forcing unwanted sexual activity.

Examples of financial abuse include:

Stealing or using without your permission: your vouchers, food stamps, disability or bank checks, credit cards, cash, or personal identification. Stealing your medical equipment, medicine, possessions, food, clothing, car, etc.

All sexual encounters you have with another person should be consensual. Consent means that all people involved have agreed to the sexual act and show that they are enthusiastic. If someone is touching you in violent and/or sexual ways without your permission, that is not consent. Forced sexual contact is called rape, sexual assault, or sexual abuse.

Call the Chicago Rape Crisis Hotline at 1-888-239-2080 for immediate services.

Those living outside of Chicago can call the Rape, Abuse & Incest National Network's (RAINN) National Sexual Assault Hotline at 1-800-656-HOPE to be connected to a local rape crisis hotline or center.

If you are being or have been abused know that this is not your fault. If you think you are experiencing any type of abuse tell a teacher, social worker, Access Living employee, parent, friend, or someone else you trust.

In Chicago you may want to consider the following:

Sinai's Domestic Violence Program is the only program of its kind in the Chicagoland area that is specially designed for people with disabilities. It offers a confidential hotline, peer support, and legal advocacy for people with disabilities. For more information about Sinai's program, contact:

Illinois Certified Domestic Violence Professional
1401 S. California Boulevard
Chicago, IL 60608-1797
Phone: 773-522-6405
Fax: 773-522-1709

A Note on Mental Health

Reproductive Health is just one important part of a person's physical health. Seeing a physician, dentist, and other specialists is also important to your physical health. One aspect of health that is often overlooked, however, is mental health.

WHAT IS MENTAL HEALTH?

Mental health includes our emotional, psychological, and social well-being. Having low energy, feeling sad and angry frequently, or experiencing mood swings can all be signs that you may want to seek help from a mental health professional. If you are having thoughts of harming yourself or others you should definitely seek mental health treatment.

Making an appointment with a therapist, counselor, psychologist or psychiatrist can help people heal after traumatic events or simply allow one to process and cope with the emotions that come with daily life. Mental health is important for people of all ages and backgrounds. Because there are many false stereotypes surrounding mental health services and those who receive them, it is important to remember that seeking mental healthcare is actually a common and important practice.

HOW DO YOU FIND A DISABILITY FRIENDLY THERAPIST?

Finding a therapist who is disability friendly can be difficult. Beyond physical accessibility into the building, it is important that your therapist is not ableist. If you are working with someone who talks down to you, makes negative assumptions about you because of your disability, or acts in other ways that make you uncomfortable, it is okay to request to start seeing a different person. Talking to other people with disabilities, doing research, and asking questions before making an appointment are steps you can take to find a therapist that is a good fit.

Mothering with a Disability

by Judy Panko Reis

More and more women with disabilities are choosing to become mothers. Some are choosing to become pregnant and others are adopting children. Despite the growing numbers of women with disabilities who are mothers, some still face legal and medical barriers to having or adopting children and keeping custody of their children. The good news is that there are more disability-sensitive providers than ever to care for you when you become pregnant.

RESOURCES

There are more resources now to help you learn about your rights to bear or adopt children, raise them, and retain custody of them than ever before. Some of these resources are in communities and many others are on the internet. Two of the best internet resources available to you are:

- National Council on Disability, "Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children," www.ncd.gov/publications/2012/Sep272012/
- Through the Looking Glass, www.lookingglass.org

These resources can help you get connected with other moms with disabilities or identify disability friendly equipment such as baby furniture or devices for your wheelchair to help you carry your child. In rehabilitation hospitals, you can connect with an occupational therapist (OT) who can help you determine which supports and strategies work best for you, your child, and your disability. Your OT can partner with you to find out which techniques are easy and safe for you and your child.

RIGHTS

It is important for moms with disabilities to understand that you do not need to be a "super mom" to prove that you are a good mom. With the right supports and resources, you have the same possibilities of providing quality child care that moms without disabilities provide to their children. You have the same rights and responsibilities as moms without disabilities, meaning that you have the right to be the primary decision maker in all of your child(ren)'s care. Like other moms, you also have the right to use the help of others to provide the safe loving care your child(ren) deserve(s).

Even if you cannot be functionally independent to feed or dress your child, it is still you who will make the decisions regarding your child. For example, it is still your right to determine how and when a helper can assist you in the feeding or dressing of your child even if your disability prevents you from physically feeding or dressing your child. If you are not comfortable about making these decisions about your child, it is important that you, a family member, or an advocate contact a disability-friendly parenting agency such as Through the Looking Glass to determine how you can best meet the physical, emotional, and safety needs of your child.

One more important point for moms with disabilities who are using home based services is the fact that Illinois does not regard parenting as “an activity of daily living.” This means that the state does not allow you to use your state-funded personal attendant to assist you with the tasks of mothering your child such as feeding, dressing, bathing, and transporting your child. If you have questions about this subject, it is best to contact your local Department of Rehabilitation or agency providing home and community-based services so that you do not risk losing custody of your child or your eligibility to receive state-funded personal attendant services.



Advice from a Fe Fe

KANDACE ROBINSON has been involved with the Empowered Fe Fes at Access Living for two years. She is twenty-five years old and the mother of a one year old, Krystle Aaliyah Robinson. Kandace shared the advice she has for other women with disabilities on pregnancy, doctor's appointments, and raising a child.

Stay Calm

“I was scared because I never thought it would be me but my friend helped me told me ‘your baby gonna love you, it’s gonna get hard but come to me if you have any questions. Don’t be afraid.’ They doubted me a lot but I overcame it. I was listening to what my grandma said and what everyone said. They think people with disabilities can’t have babies but we can.”

Take Care of Yourself

“Be careful. Watch what you eat. Listen to your doctor. Take your medicine. Go to your doctor appointments on time. Stay calm. Don’t panic. Everything will go fine.”

Work with Your Gynecologist

“My gynecologist gives me papers, pamphlets, she’ll give me advice, she helps me and tells me ‘everything’s gonna be fine.’ To this day she still helps me.”

Enjoy Motherhood

“Raising a baby is hard but it’s gonna get easier. My favorite part about being a mom is the joy of having her, it just makes me complete. She smiles a lot, she keeps me happy, she keeps me motivated.”



Kandace Robinson and
Senator Emil Jones III,
Springfield, IL 2014

Hospital Evaluation Findings and Recommendations

The Empowered Fe Fes and Access Living staff and consumers set out to answer a tough question when doing research for this guide: Which reproductive healthcare providers in Chicago are the most accessible and disability friendly?

We felt it was important to answer this question because there is a lack of research in this area, and we knew that our survey would help women with disabilities find local quality healthcare.

After identifying different reproductive healthcare providers in Chicago, we chose seven hospitals and clinics to survey. Many of the clinics and hospitals we chose are federally funded. Seven people made phone calls to the clinics we chose to survey. Our volunteers all identify as women with disabilities.

The criteria on which we judged the hospitals and clinics were:

- Accessibility to people with physical disabilities
- Willingness/ability to make specific accommodations for patients
- Knowledge and quality of customer service demonstrated by the receptionist
- Overall experience of the phone call

Within the evaluations that were filled out by those who made phone calls, we saw some common trends occurring in access to reproductive healthcare in Chicago:

1. Majority of the hospitals and clinics said that they have accessible entrances and exits.
2. Some hospitals and clinics have adjustable exam tables but said that they will not help with transferring from wheelchair to exam table if you cannot transfer by yourself.
3. Half of the hospitals said that they are not able to assist with helping patients with dressing and undressing as a personal accommodation.

The Empowerment Fe Fes cannot promise accessible and disability friendly service at these sites. This information was provided by the people answering the phones at these hospitals and clinics, and is a recommendation only. It is your choice to use this resource for your health care access. We also recommend asking questions about accommodations when you call to schedule an appointment and educating your hospitals and clinics about accessibility.

Note: Questions answered N/A signal that accomodation did not apply to the tester. Disability specific providers are featured on page 46.

Planned Parenthood Wicker Park Health Center
1152 North Milwaukee Avenue, Chicago, Illinois 60642
Phone: (773) 252-2240

Are the entrances, exists, and bathroom doors at this site accessible? **Yes**
If I go to this site, can I get assistance transferring on and off the exam table? **Yes**
Are there adjustable height exam tables at this clinic? **NA**
Do they provide help getting dressed or undressed? **Yes**
Can I receive assistance with positioning during exams? **Yes**
Is it easy to access written directions in accessible formats here? **Yes**
www.plannedparenthood.org/health-center/illinois/chicago/60642/wicker-park-center-2267-90430

Planned Parenthood Austin Health Center
5937 West Chicago Avenue, Chicago, Illinois 60651
Phone: (773) 287-2020

Are the entrances, exists, and bathroom doors at this site accessible? **Yes**
If I go to this site, can I get assistance transferring on and off the exam table? **Yes**
Are there adjustable height exam tables at this clinic? **No**
Do they provide help getting dressed or undressed? **NA**
Can I receive assistance with positioning during exams? **NA**
Is it easy to access written directions in accessible formats here? **NA**
www.plannedparenthood.org/health-center/illinois/chicago/60651/austin-health-center-2265-90430

Planned Parenthood Loop Health Center

18 South Michigan Avenue, 6th Floor, Chicago, Illinois 60603

Phone: (312) 592-6700

Are the entrances, exists, and bathroom doors at this site accessible? **Yes**

If I go to this site, can I get assistance transferring on and off the exam table? **No**

Are there adjustable height exam tables at this clinic? **No**

Do they provide help getting dressed or undressed? **NA**

Can I receive assistance with positioning during exams? **NA**

Is it easy to access written directions in accessible formats here? **NA**

www.plannedparenthood.org/health-center/illinois/chicago/60603/loop-health-center--3286-90430

University of Chicago Obstetrics and Gynecology

Duchossois Center for Advanced Medicine (DCAM), Clinic 3H

5758 South Maryland Avenue, Chicago, Illinois 60637

Phone: (773) 702-6642

Are the entrances, exists, and bathroom doors at this site accessible? **Yes**

If I go to this site, can I get assistance transferring on and off the exam table? **Yes**

Are there adjustable height exam tables at this clinic? **Yes**

Do they provide help getting dressed or undressed? **No**

Can I receive assistance with positioning during exams? **Yes**

Is it easy to access written directions in accessible formats here? **NA**

chicagofertility.uchicago.edu/

Rush Associates in Women's Health

1725 West Harrison Street, Professional Building III, Suite 762

Chicago, Illinois 60612

Phone: (312) 942-8120

Are the entrances, exists, and bathroom doors at this site accessible? **Yes**

If I go to this site, can I get assistance transferring on and off the exam table? **No**

Are there adjustable height exam tables at this clinic? **NA**

Do they provide help getting dressed or undressed? **No**

Can I receive assistance with positioning during exams? **Yes**

Is it easy to access written directions in accessible formats here? **NA**

myrush.rush.edu/PhysicianPractices/rawh/Pages/default.aspx

University of Illinois at Chicago Hospital,

Obstetrics and Gynecology

Outpatient Care Center Center for Women's Health

1801 West Taylor Street, Suite 4C, Chicago, Illinois 60612

Phone: (866) 600-2273 (for new patients)

Are the entrances, exists, and bathroom doors at this site accessible? **Yes**

If I go to this site, can I get assistance transferring on and off the exam table? **NA**

Are there adjustable height exam tables at this clinic? **NA**

Do they provide help getting dressed or undressed? **NA**

Can I receive assistance with positioning during exams? **NA**

Is it easy to access written directions in accessible formats here? **NA**

hospital.uillinois.edu/Patient_Care_Services/Obstetrics_and_Gynecology.html

Northwestern University Prentice Women's Hospital

250 East Superior Street, Chicago, Illinois 60611

Phone: (312) 926-2000

Are the entrances, exists, and bathroom doors at this site accessible? **Yes**

If I go to this site, can I get assistance transferring on and off the exam table? **Yes**

Are there adjustable height exam tables at this clinic? **Yes**

Do they provide help getting dressed or undressed? **NA**

Can I receive assistance with positioning during exams? **NA**

Is it easy to access written directions in accessible formats here? **NA**

nm.org/location/prentice-womens-hospital

Our Recommendations for Healthcare Providers

1. Education and training should be provided to doctors and other healthcare staff about people with disabilities, and their healthcare needs.
2. Under titles II and III of the Americans with Disabilities Act (ADA), medical facilities must ensure that their services are accessible to people with disabilities. We recommend medical facilities to be fully accessible including the examination room and all medical equipment.
3. Medical providers should have accessible and inclusive programs and conduct outreach and education that target the disability community.



Passing the Torch: Your Turn

We hope that this reproductive health guide has given you new information about reproductive healthcare and women with disabilities. Using what you now know, there are many steps you can take from here to keep up with your health and help educate others about these issues. Where one wants to go from here will look different for different people. If you haven't done so before, make an appointment with a gynecologist. If you haven't been in a while, check in with your gynecologist to see when your next appointment should be.

Take this guide to your healthcare providers and have conversations with them about how they can make your experience more accessible and what things they need to understand about people with disabilities.

Reach out to the resources we have listed in this guide (see next page). Talk to other women with disabilities about sexuality, healthcare, and/or parenting.

If you live in Chicago and are interested in advocacy work, come by Access Living or join the Empowered Fe Fes. If you live in other areas, research what similar organizations are near you or start your own.

Whatever it is that you do, do something! It is going to take all of us to reclaim sexuality for people with disabilities, challenge the medical model, and pave the way for future generations to be treated better by medical systems.

Now, it's your turn.

Resources for Women with Disabilities

CLINICS AND PROGRAMS

Mile Square Health Center, Humboldt Park

3240 West Division Street, Chicago, Illinois 60651-2405

Phone: (312) 413-7425

Fax: (312) 413-2588

Hours: Monday – Friday

9:00 am – 12:00 pm; 1:00 pm – 5:00 pm

This center provides a full range of women's care including birth control, pelvic exams, midwifery, birthing options, and menopause management. The clinic is equipped with accessible scales, lift equipment, adjustable examination tables, and accessible gynecological exam tables.

Schwab Rehabilitation Hospital's Domestic Violence Services Program

Illinois Certified Domestic Violence Professional

1401 South California Boulevard, Chicago, Illinois 60608-1797

Phone: (773) 522-6405

Fax: (773) 522-1709

Sinai's Domestic Violence Program is the only program of its kind in the Chicagoland area that is specially designed for people with disabilities. Our domestic violence program offers a free 24-hour confidential hot line care to people with disabilities. This program provides advocacy and support to disabled people who have experienced or are experiencing physical, emotional, or financial abuse or neglect.

COMMUNITY ORGANIZATIONS

Between Friends

2301 West Howard Street, Chicago, Illinois 60645

Phone: (773) 274-5232

TTY: (773) 274-6508

Toll Free Crisis Line: (800) 603-HELP

www.betweenfriendschicago.org

Between Friends is an organization dedicated to breaking the cycle of domestic violence and building a community free of abuse. Their services include counseling for victims and their children, court advocacy, and prevention and education efforts.

Center on Halsted

3656 North Halsted, Chicago, Illinois 60613

Phone: (773) 472-6469

www.centeronhalsted.org

The Center on Halsted is committed to advancing Chicago's Lesbian, Gay, Bisexual, Transgender, Queer (LGBTQ) and allied community. To do so they provide a variety of programs and services including but not limited to programs for young people, group therapy, and testing for sexually transmitted infections.

Empowered Fe Fes

Access Living

115 West Chicago Avenue, Chicago, Illinois 60654

Phone: (312) 640-2100

TTY: (312) 640-2102

Toll Free: (800) 613-8549

www.accessliving.org

We want to hear from you! The Empowered Fe Fes is a young women's advocacy and peer support group that is committed to creating change in the lives of young women with disabilities. To learn more, call Access Living and ask for Fulani Thrasher, our Women and Girls organizer.

Illinois Caucus for Adolescent Health (ICHA)

226 South Wabash Avenue Suite 900, Chicago, Illinois 60604

Phone: (312) 427-4460

www.ichah.org

ICHA's mission statement reads, "ICHA is a network of empowered youth and allied adults who transform public consciousness and increase the capacity of family, school, and healthcare systems to support the sexual health, rights, and identities of youth." The organization has a strong focus on education and advocacy and many opportunities for youth to get involved.

Rape Victim Advocates

180 North Michigan Avenue, Suite 600, Chicago, Illinois 60601

Phone: (312) 443-9603

Rape Crisis Hotline: 1-888-239-2080

www.rapevictimadvocates.org

Rape Victim Advocates work provides individual and group counseling to survivors of sexual assault. Their advocacy work centers around changing the ways institutions respond to survivors.

WEBSITES**MAP to Access**

www.projectvision.net/map/home.html

Medical Access Program (MAP) provides people with disabilities information and tools to advocate for themselves at the doctor. The website has quite a bit of information, so we wanted to point you to a few of our favorite parts. The stories section provides personal accounts of medical access issues. You can also find fact sheets that pertain to your particular disability. The access video we highlighted in the self-advocacy section in this guide can be found in the "Individuals" section of the MAP website.

Scarleteen

www.scarleteen.com

As you can see when you first pull up their website, scarleteen provides "inclusive, comprehensive, and smart sexuality information and help for teens and 20s." Although it is geared toward young people, this is a great resource for all ages. The website has a wealth of information about sexual politics, relationships, pregnancy, parenting, sexuality, and other topics. If you can't find what you are looking for, you can always ask a question on one of their message boards.

PUBLICATIONS, ARTICLES, REPORTS, AND BOOKS

“10 Amazing Products For Parents With Disabilities”

Parenting with a disability is a lot easier with adapted products designed by occupational therapists. Check out some of these disability friendly parenting products at www.themobilityresource.com/10-amazing-products-for-parents-with-disabilities/

“Breast and Cervical Cancer Screening Disparities Associated with Disability Severity,” *Women’s Health Issues*, 2014

Women with disabilities are known to experience disparities in reproductive healthcare. Dr. Lisa Iezzoni, Harvard Medical School researcher and woman with a disability, coauthored this article outlining the problems women with disabilities face in being screened for breast cancer and cervical cancer.

Enabling Romance: A Guide to Love, Sex, and Relationships for People with Disabilities (and the People Who Care About Them)

This guide by Ken Kroll and Erica Levy Klein reminds us that sexual happiness belongs to us. Information on reproduction, birth control, the shattering of sexual stereotypes, building self-esteem, and different types of physical disabilities is included.

“Know Me Where It Hurts: Sex, Kink, and Cerebral Palsy”

This online article is written by a woman with cerebral palsy who discusses her sexual preferences and struggles with body shame. www.autostraddle.com/know-me-where-it-hurts-kink-cerebral-palsy-226077/

Our Bodies, Ourselves

This book collective promotes accurate information on girls’ and women’s reproductive health and sexuality. The 35th anniversary publication, *Our Bodies, Ourselves: A New Edition for a New Era* (2005), includes a chapter entitled “Sex and Disability” (pp. 215-223).

Our Rights Right Now

A toolkit published by The Illinois Imagines Project, a collaboration of disability, governmental, and self-advocacy organizations, about improving responses to sexual violence against women with disabilities. www.icasa.org/docs/illinois%20imagines/mini%20module%201%20overview.pdf

PleasureABLE: Sexual Device Manual for Persons with Disabilities

This manual was created specifically for people with disabilities and healthcare providers who work with people with disabilities. The guide includes information on research, clinical expertise, sexual device products, and other topics. www.dhrn.ca/files/sexualhealthmanual_lowres_2010_0208.pdf

“Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children”

The National Council on Disability’s groundbreaking 2012 report on parenting with disabilities examines barriers and discrimination faced by parents with disabilities and offers policy recommendations. www.ncd.gov/publications/2012/Sep272012/

Sexual Politics of Disability: Untold Desire

This book by Tom Shakespeare raises issues about civil rights in the area of disability and sexuality, attacking the taboos around disability and sex.



Established in 1980, Access Living is a change agent committed to fostering an inclusive society that enables Chicagoans with disabilities to live fully-engaged and self-directed lives. Nationally recognized as a leading force in the disability advocacy community, Access Living challenges stereotypes, protects civil rights, and champions social reform. Their staff and volunteers combine

knowledge and personal experience to deliver programs and services that equip people with disabilities to advocate for themselves. Access Living is at the forefront of the disability rights movement, removing barriers so people with disabilities can live the future they envision.

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What Does Access Living Do?

Information and Referral

Information about any disability-related subject and referral to other resources when needed.

Advocacy

Ongoing direct, nonviolent action in support of disability rights, at the individual, community, and national level.

Independent Living Skills

Real-life training on practical know-how for living independently, from budgeting to traveling, personal assistant management to job seeking, and more.

Peer Counseling

Real problem-solving skills and support for all kinds of issues with other people with disabilities who understand exactly what it's like.

Youth

Access Living's Ready Program will support low-income youth with disabilities transitioning out of high school. Working with the Chicago Public Schools and other partners, the program will form a new youth institute that will equip youth with disabilities with the resources needed so that they can be successful and independent.

