Sexuality



Sexuality is a natural part of life. For many women, sex is a way to feel pleasure, to express love and desire for their partners, or to become pregnant with the children they hope for. But sexuality is more than having a sexual relation with someone. The way a woman is intimate with her partner, the way she relates to her own body and the way she thinks about herself as a woman are all part of her sexuality.

Women with disabilities can have, want to have, and have the right to have and enjoy close, loving, sexual relationships. Sometimes community attitudes influence or limit how women with disabilities experience their sexuality. If people in a community understand and agree that women with disabilities have the same needs for love, sex, and family as everyone else, then a disabled woman is able to:

- express sexuality in a way that gives her pleasure.
- choose her sexual partner.
- negotiate when and how to have sex.
- choose if and when she becomes pregnant.
- prevent sexually transmitted infections.
- be free from sexual violence, including forced sex.

We have the right to be loved for who we are, not for what we cannot do or what we look like.

Harmful beliefs about disabled women's sexuality

Some harmful beliefs about the sexuality of women with disabilities are described below. Many women with disabilities say these negative attitudes and beliefs disable them from enjoying close, loving, sexual relationships. Sometimes these wrong attitudes prevent women from finding faithful spouses and partners who respect and value them.



Harmful belief: Disabled women's bodies are shameful

In most communities, women are valued by a standard of physical attractiveness. If a woman looks very different from that standard, people may not think she is 'worthy' to be married or to be a sexual partner.

Gita tells us about "perfect" marriage partners

In India, the problem is that we look for perfect people with perfect bodies. So much importance is given to physical appearance that there's no place for a person who is 'imperfect.' Just take a look at the matrimonial advertisements today—all the men want women who are slim, beautiful, fair-skinned, educated, of good breeding, etcetera. There is also a belief that if a boy marries into a family where one of the family members has a disability, his children will be born with that disability. It happened to me, so I know. There is a very strong gender aspect to this. It is the women who are expected to be perfect in every way. On the other hand, the groom could be disabled, ugly, epileptic, alcoholic, and he's still the perfect groom!



Harmful belief: Disabled women cannot have sexual feelings

Like other women, women with disabilities have sexual feelings. But members of her family or community may think she should not or cannot have sexual feelings.

Sometimes, a woman with a disability comes to believe she does not have sexual feelings and no one will be sexually attracted to her or want to have babies with her. If a

My deafness does not prevent me from having sexual feelings, just as wearing glasses does not prevent you being thirsty or hungry!

woman is born with a disability, or if she became disabled as a young child, she may have a hard time believing she is sexually attractive as she grows and develops. If a young woman becomes disabled when she is starting to explore her sexuality, her self-image may be hurt and she may not believe she will ever have a sexual relationship.

Even an older woman who has developed and experienced her sexuality may change how she feels about her body after becoming disabled. She may think she is not sexually attractive anymore or feel sad that sex would be different now. She may not realize she can continue to enjoy sex.

Harmful belief: Disabled women always want sex

Some people think women with disabilities—especially women who have difficulty learning or understanding—always want sex. But this is not true.

Just like any group of women, disabled women have a variety of preferences. Some like to have sex often, and some do not like to have much sex at all.

Like any woman, a woman with a disability should be able to choose when she wants to have sex. And every woman must be able to say no to sex she does not want.

Prevent sexual abuse of girls and women who have trouble learning or understanding

Many girls and women with disabilities do not get enough attention or chances to develop the close relations they need.

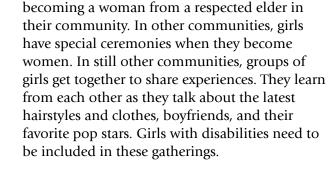
If you are left at home or ignored by your family, you may be lonely and look for a friend or someone else who will pay attention to you. Other people can mistake this need for attention with a desire for sex. Or they may try to take advantage of you, because you are alone or because they believe no one will care if they hurt you.

It can also be hard to express what you really want, especially if you have not been taught about sex. It is very important to learn about your body and about sexuality. Someone you trust can help you protect yourself and make good decisions about sex.

Learning about sexuality

Too many girls with disabilities first learn about sex when someone abuses them or lures them into having sex. Health workers, family, friends, and helpers can include girls and women with disabilities in talks about sexuality and womanhood. Include disabled girls in sex education programs and teach them about sexuality. This can help protect girls from men who want to take advantage of them. For information on sexual abuse, see Chapter 14.

I never got any sex
education. I heard my mum
talking with other women,
but she never talked with me.
She never expected me to
get married, so she thought I
didn't need to know.



In some communities, girls learn about



I learned about sexuality by listening to other women talking. I wish someone had spoken to me directly, so I could have asked questions of my own. My mother never told me details. If I asked for details, she threatened to hit me. Mostly, I learned from my friends.





My aunt knew I could get married. She taught me about being a woman, just like she taught other girls.



Girls and women with disabilities need to learn about becoming a woman, about sexuality, and about relationships.

FINDING A LOVING PARTNER

Like other women, you deserve a partner who respects you and cares for you. You deserve a partner who will listen to you and who treats you well. You deserve to find someone who loves you for who you are—a partner who values your strengths and who will help you with your limitations. You deserve a partner who wants your help, your trust, and your love.

Many women who find loving partners say they refused to believe wrong ideas about disability. They gained skills and found ways to contribute to their families. And they learned to respect themselves. When you respect and value yourself, you are more likely to find a partner who respects you too. For information on self-esteem, see pages 62 to 65.



After my accident, I developed a hunched back and had a hard time moving around. But I found a loving man who was drawn to my personality and my courage. He likes the way I laugh away my troubles. When he asked me to marry him, I agreed.

Now we have a beautiful child.

Before my partner asked me to marry him, we talked openly about my disability. He told me that he accepted me as I was, including my limitations. He promised never to be ashamed of me. We have a marriage based on trust and respect—and we also have two children.





My husband and I fell in love when we were working together. Our parents met and arranged the marriage for us. His mother was very good to us, but some of his relatives did not want to accept me. My husband is a government official and they thought he would not be able to travel with a disabled wife. At first, I was hurt by their opinions. But with my husband's support, we have been able to travel together and build a strong partnership.

When a girl with a disability learns job skills and gets an education, she is more likely to find a loving partner. A job usually gives her more opportunities and stronger self-esteem. And it is easier for other people to believe that a woman with a disability who has a job is someone who could contribute to the family.

ABUSIVE PARTNERS

Sometimes a woman feels she must settle for any partner, even one who abuses her, or one who may not care for her or provide support for her or her family. Sometimes a woman accepts a person who will help bring money and support her family. Or a woman may trade sex for food or for the help she needs to survive. At other times, it is the woman who works and the man who takes her money. He tells her she should be grateful to have him.

When a woman is valued by her family, community, and herself, she has sexual relationships with people who treat her well. She will not accept partners who hit or abuse her.

Arranged marriages

In some communities families arrange marriages for their daughters. When this happens, a disabled woman is often treated as less valuable than any other woman. Her family may arrange her marriage with anyone who will accept her, even if her future husband will not treat her well. The woman herself may agree to the marriage because she does not value herself or she thinks no one else will want to marry her.

Sometimes the husband demands a bigger dowry or other payments from the family because the woman has a disability. Or the disabled woman becomes a second wife and is not treated as well as a non-disabled wife. If a man asks for more money or gifts to make up for a woman's disability, it is a sign that he does not respect her as a woman. Often, he will abuse her in other ways as well (see Chapter 14).

Midnight husbands

In some countries, a man will visit a disabled woman only at night, to have sex with her. Then, he will leave before morning, while it is still dark. These men are sometimes called midnight husbands. They usually stop visiting the woman if she becomes pregnant, and they almost never give any financial support for the child.



FEELING PLEASURE FROM SEX

It is natural for a woman to want to share sexual pleasure with her partner. But sometimes a woman may not feel pleasure from sex. There can be many reasons for this. If her partner is a man, he may not realize that a woman's body responds differently to sexual touch than a man's body does. The woman may have been taught that women should enjoy sex less than men, or that she should not tell her partner what she likes, whether her partner is a man or a woman.

A woman's disability may make it harder for her to feel pleasure. She may need to find different ways to have sex that feel good—especially if she has only recently become disabled. Just as she takes care of her daily personal hygiene in ways that work for her disability, she can also be sexual in ways that work for her disability to bring her pleasure.



A woman can have sex with a man, a woman, or with herself.

HOW THE BODY RESPONDS TO SEXUAL PLEASURE

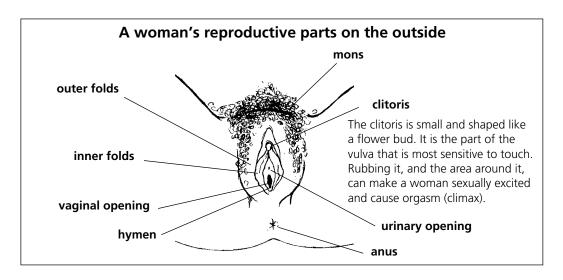
Both women and men feel sexual desire, but their bodies respond differently to sexual thoughts and touch. When men and women have sexual thoughts or are touched in a sexual way, they feel excited. More thought and touch make the body more excited. It is easy to see sexual excitement in a man, because his penis gets hard.

The woman's body also gets excited, but it is harder to see. The clitoris gets hard and may swell, and the labia and walls of the vagina become sensitive to touch. The vagina becomes wet with a clear, slippery fluid. Her nipples too may swell and become sensitive.

If sexual touch and thought continue, sexual tension builds up until she reaches her peak of pleasure and has an orgasm (climax). When orgasm happens, the energy and tension is released throughout the body, especially in the vagina. Generally, after orgasm a woman feels relaxed and full of pleasure.

When a man reaches his peak of pleasure, his penis releases semen, a fluid containing sperm (ejaculation). After orgasm, his body relaxes and his penis becomes soft again.

Touching the clitoris is the most common way a woman reaches orgasm. It may also happen from rubbing inside her vagina, with a penis or with fingers. Her breasts and anus may also be sensitive to touch. It often takes longer for a woman to reach orgasm than a man.



It is possible for most women to have orgasms, but each woman's body and experience is different. Women who have less feeling in their lower body may need more pressure and firm touching on their clitoris, sometimes at the same time as pressure in their vagina, in order to have orgasm. Even women with spinal cord injury and women who have no feeling in their bodies do have orgasms, though they may feel them differently.

Different women have different places on their bodies where they feel pleasure and like to be touched. Most people think of a woman's genitals or breasts as the "sexual" parts of her body. But a woman's hands, neck, face, and belly can also be sensitive areas that give her pleasure when they are touched. For women who are paralyzed or have a spinal cord injury, these other areas can become so sensitive that they can feel pleasure like orgasms because of being touched.

All the senses—touch, smell, hearing, taste, and sight—can be important and satisfying ways to feel sexual pleasure. Each person, man or woman, with or without a disability, experiences these senses in his or her own way. For a blind woman, touch, smell, and hearing might be most important. For a deaf woman, touch and sight may be the most satisfying parts of sex.

A woman can learn about the sensitive parts of her body and about how to have an orgasm by touching herself, or by letting her partner know what feels good. This will be especially helpful for a woman who has recently become disabled. It may make her partner feel good to know how to please her.

Different ways of having sex

There are many different ways people have sex and share pleasure together. People often think of sex as only between a man and a woman, and only with a penis in a vagina. But there are many other ways people have good sex and express their love with another person. Sex is not just about a person's genitals. Kissing, hugging, and talking are part of having sex. Touching a person's face, hands, back, and neck are also good ways of being sexual. Having oral sex (when one partner—or both—puts his or her mouth on the other's genitals and licks or sucks) may be pleasurable. Touching and rubbing each other's genitals (mutual masturbation) may be another way to give and get sexual enjoyment.

Touching oneself for pleasure (masturbation)

You can touch yourself in a way that gives you sexual pleasure. This is a good way to learn about your body and what kinds of sexual touch feel best. It can also help you feel more confident and good about your own sexuality. Many communities have

beliefs that touching oneself is wrong or harmful, so sometimes people feel shame about doing it. But touching yourself does not cause harm or use up sexual desire. It can be a good way to feel pleasure and satisfy desire whether or not you have a partner.

SEX IN A RELATIONSHIP

Most women want to have a close and loving relationship with someone who cares for them. These relationships may be with other disabled persons, or with non-disabled persons. Some disabled women are married, and others are not. Many disabled women have relationships with men, and some have relationships with other women. Some are mothers, others are not.

For women with disabilities and their partners, sex is often more enjoyable for both people if they are willing to experiment and find new ways of doing things. Instead of focusing on things you cannot do (or things that are hard to do), build on things you can do that bring pleasure to both you and your partner.

Talking with your partner

Many women are ashamed to talk about—or feel—their desires. But it is natural to feel desire and to want a relationship that makes you feel good. If you plan to have sex with someone, it will help to talk with that person ahead of time about things like safer sex (see pages 180 to 182) and family planning (see Chapter 9).

Talk with your partner about any limitations in your movement and about ways in which your body may respond to sexual stimulation. Sometimes a partner worries that sex will hurt a woman or be dangerous because of her disability. This can lead to lack of desire. When each partner knows the kind of sexual talk and touch the other likes, they can both enjoy sex more. Each person's desires are different, so the best way to learn what another person likes is to talk with one another and experiment.



Good things to talk about are:

- where it is easier to have sex. For example, on the bed, in your wheelchair, in a chair, or on the floor.
- what position hurts or could be more comfortable.
- how your disability affects how your body works.
- how you can give each other pleasure, and what does not feel good.
- if you tire easily, what times of the day or week you may have the most energy for sex.

If your partner is also your caregiver, it can be helpful to talk about the difference between the time you spend together for care and the time you spend together as sexual partners.

IMPORTANT Whether a woman has a sexual relationship with a man or another woman, it is important to practice safer sex to prevent sexually transmitted infections, including HIV. If you or your partner have had sexual relations with someone else, it is also important to go for an HIV test before having sex with your partner. For more information, see page 172. Also, if you want to have sex but do not want to get pregnant, see Chapter 9 for information about family planning, and page 205 about emergency contraception.

Sexuality for women who become disabled

A woman who becomes disabled due to an accident or illness may find that her sexual feelings change. Some women have fewer sexual feelings or are not interested in sex for a while. Sometimes women think they are no longer able to experience pleasure or enjoy sex. Every woman needs information about how her disability affects her sexuality. And if she has a partner, they both need information about how sexuality can be affected by disability.



If you were in a sexual relationship before you became disabled, you may be afraid to try having sex again. You may be concerned that your partner will not find you sexually attractive anymore. Or both you and your partner may be concerned that you will not be able to satisfy each other any more. It is helpful for you both to talk about your feelings and the changes you may need to make. The way you have sex may be different, but like most other couples, you will find ways to have sex and please each other. This is especially true if you had a trusting relationship and good communication before the disability.

PRIVACY

Finding a good time and place to have sex can be hard for women with disabilities, especially if they need someone else's help to get ready for sex. It can also be hard for women who live with their parents or other relatives.

There is no easy answer to this problem, especially if your family or caregivers do not think you should have sex. Sometimes, it can help to talk with the people who are helping you. Or you can try talking with another person you trust, who can then talk to your family or helpers. It is also helpful to talk with other women with disabilities, and to share experiences.

Some people find ways to manage on their own. For example, a woman can have sex with her partner while she is in her wheelchair. Then she does not need another person to help move her to a bed. And some people find that their helpers are sensitive to their needs and want to support their relationships.

Let's go together to speak with your mother-in-law. We will tell her that when your husband comes home, you would like to spend some time alone with him in a private place.



FINDING A COMFORTABLE POSITION

If you have limited movement you may have to experiment to find a comfortable position to have sex. Women with cerebral palsy, weak muscles, tight or spastic muscles, or arthritis, and women whose disability causes pain or weakness, may need help from a partner to find a comfortable position. It may help to use pillows or rolled-up cloth to support your legs or hips. Also, if a partner's weight causes pain, try a position where you both lie on your sides, or sit in a chair together. Kissing and touching may be easy to do, but having sex with a penis in the vagina or anus may be difficult.

I feel like a queen now because I am always in my chair when we have sex. It adds to the excitement.

Oral sex is easier if both people can get their bodies into the right position.

If you are paralyzed, you probably know how much you can move and what body positions are possible for you. Depending on how much of your body is paralyzed, it may be necessary to ask a partner or trusted caregiver for assistance.

The positions used for having a pelvic exam can also be used for sex (see page 133). And the "safer sex" positions listed on page 182 may also be helpful.



Possible problems during sex

Pain during sex

Sex should not hurt. Sometimes the pain is due to a woman's disability, but often there are other causes. Sometimes a woman feels pain when a man's penis, or a partner's fingers or hand, enters her vagina. This can happen when:

- her partner enters her too soon, before she is relaxed and her vagina is wet enough.
- she feels guilt or shame, or does not want to have sex.
- she has an infection or growth in her vagina or lower belly.
- she has had her genitals cut or stitched together (female genital cutting or infibulation).

Some women with tight, spastic muscles, and some women with spinal cord injury, may find it painful for anything to enter the vagina. If so, try to find another way to have sex that brings pleasure for both partners.

Dry vagina

Sex can be painful if the vagina is too dry. When a woman is sexually excited, her vagina usually becomes wet. This is natural. But sometimes a woman's disability makes it less likely for her vagina to become wet. This can happen to many women, but especially to some women with rheumatoid arthritis and spinal cord injury.

A common way to make the vagina wetter is to take more time with sex, so that the body makes more of its own wetness. You can also use a lubricant to make the vagina slippery so the skin will not tear.

IMPORTANT If a latex condom is used during sex, do not use oil, petroleum jelly (*Vaseline*), butter, mineral oil, or lotion to make the vagina wetter. These can make the condom break. Use a water-based lubricant, such as *KY Jelly*, with a condom.

In some places, people prefer to have sex when the vagina is very dry. So some women put herbs or powders in their vaginas, or wash out (douche) their vaginas before sex. But when the vagina is dry, it can become irritated during sex, making it more likely to become infected with HIV and other STIs.

Painful muscles and joints

Sometimes a disability, such as arthritis, will cause a woman to have pain when she moves around more than usual. If this happens to you, heat can help ease pain. Use cloths soaked in warm water on painful or swollen joints, or take a warm bath before you have sex. This can help your body relax so you enjoy sex more. If you use medicines to help your pain, try taking them at a time of day that will help you feel good when you are getting ready to have sex.



Muscle spasms

When a woman with a disability such as cerebral palsy or a paralysis becomes sexually excited, her muscles may suddenly get tight (muscle spasms). A muscle spasm is not dangerous or harmful, unless it goes on for a long time. You do not need to stop having sex. Sometimes, pressing gently on the tight muscle can help ease the spasm. Sometimes, gently stretching the muscle can also ease the spasm. But do not pull on the muscle or try to break the spasm. If you take medicine to prevent muscle spasms, it may help to take the medicine before having sex.

Bladder and bowel care

It is best to pass stool and urine before having sex. Also, if a leg bag is used to collect urine from a catheter, make sure it is empty. To avoid bladder and bowel accidents during sex, it may help to not drink or eat for a short while before sex.

If a urine catheter stays in all the time, it can be taped or tied out of the way during sex. Make sure the tube does not get bent or twisted. It is also possible to take out a fixed (Foley) catheter for up to 4 hours. But before you do this, great care must be taken to prevent infection (see pages 102 to 104). Usually, it is best to leave the catheter in during sex.

If a woman removes her catheter during sex, she will likely pass urine during sex. Because of the catheter, her bladder is not used to holding urine inside and urine will leak out. There is also a chance she will pass stool during sex. Keep a cloth or towel close by to catch the urine or stool if this does happen.

It can help to discuss the possibility that this may happen ahead of time with your partner. This is a difficult subject, and every woman will talk about it differently. Some women treat it like any other part of life. Other women use humor and find a way to laugh about it.

IMPORTANT A condom can tear or break when it rubs against a catheter. To help prevent this, use a water-based lubrication jelly on the outside of the condom or inside the vagina.

IMPORTANT During sex, some women with a spinal cord injury can get sudden high blood pressure with pounding headaches, flushed or red skin, or a fast heartbeat. This is called dysreflexia and can be a serious health problem. To help prevent this, make sure you pass urine and stool before having sex. For more information about dysreflexia, see pages 117 to 119.

Feeling too tired

Your disability may sometimes make you feel tired for much of the day. Or you may take medications that make you feel tired. This can make you less interested in

having sex. Try to have sex at the time of day when you feel the least tired. If that is not practical, ask a health worker if it is safe to take your medicine at a different time of day.

If you get tired easily, or your muscles are not very strong, you may also find it easier to have sex more slowly or gently, because it will take less energy.

If you are feeling too tired for passionate sex, you can still find ways to give your partner pleasure, and you can ask your partner to caress you. Often, a loving touch can reduce a woman's pain and help her sleep better. It can also bring great joy to her and to her partner as well.

Lack of desire

Many things can cause a woman to feel less desire or pleasure from sex. Some of these things may come from a woman's disability, and some may come from other reasons. You may feel less desire if:



- you are tired from hard work, from not eating enough, from a new baby, or from your disability.
- you have a partner you do not like or who treats you badly.
- your disability causes you pain and it hurts to move.
- you feel badly about your body or ashamed about your disability.
- you are depressed or feel very sad most of the time.
- you have been hurt or forced by someone in the past to have sex.
- you are afraid of becoming pregnant or of getting a sexual infection.

When a woman lacks desire, her body makes less of its natural wetness, and she may need to use lubrication so that sex is not painful (see page 151).

Sex after sexual abuse and rape

If a woman has been sexually abused or raped, it usually takes a long time for her to feel good again about her body and about sex. Long after the physical signs of the violence are gone, the woman carries emotional hurts and bad memories. For more information about sex after sexual abuse and rape, see page 305.



If you lack desire for sex, try imagining the things that give you sexual pleasure. Sexual thoughts and fantasies can help you see yourself as a woman who has desires. They can also help you build excitement, which can make your vagina wet and help you enjoy sex more. Fantasy can be something you think about alone or something you share with your partner.

Working for change

Changing community beliefs and attitudes about sexuality and the right to sex for women with disabilities can take a long time. But over time, they can change.

It is important for a woman with a disability to feel good about herself. A woman who values herself will be more likely to expect a partner to respect her.

What disabled women can do

- Educate ourselves about sexuality and our own feelings.
- Talk with other disabled women or other women we trust to learn more about sexuality. Even if we did not learn about sex when we were growing up, we can always learn more now.
- Advise each other on ways to understand and enjoy our sexuality.
- Form or join a group with other disabled women to support and value each other's sexual and family life.
- Advocate to include disabled women in all education about sexuality.
- Advocate for respect for the sexual needs of all women.
- Find ways to express our sexuality and celebrate who we are as women.



Disabled women in our community have been coming together to empower ourselves as women. Together, we are finding ways to express our

femininity and sexuality. Some of us wear flowers in our hair or a bindi on our forehead. Sometimes we decorate our hands and feet with intricate henna patterns, wear anklets and jewelry, or have a ritual oil bath. All these things have helped us explore our sexuality and feel good about our bodies. We are learning to see ourselves as the kind of women we want to become.

—A group of women with disabilities from Tamil Nadu, India



What families and caregivers can do

 Treat a girl with a disability the same way other children are treated. This will help her grow up feeling good about herself, her body, and her feelings. When she grows up, it will be easier for her to have a loving, respectful relationship with her partner.



Make sure women and girls with disabilities have the same chances to develop a full social life.

- Support a girl during her teenage years when she is changing from a girl to a woman. If a girl with a disability gets good information about sexuality, is allowed to make herself look attractive, and does not face discrimination about the way she looks, she will feel good about her body and her sexuality, and her self-esteem will grow strong.
- Make sure girls and women with disabilities are included in talks and ceremonies about sexuality and womanhood.
- Support women with disabilities in their decisions about potential spouses and loving partners.
- Do not arrange marriages for a disabled woman if the husband or the family expects extra money or presents to "make up for" the woman's disability.
- Encourage people in the community to see women with disabilities as women first, with the same sexual needs as all women, and to treat them with respect.

It is normal for all people to want loving relationships. A woman with a disability is no different.

What the community can do

- Make sure women with disabilities are included and have important roles in community ceremonies about sexuality and womanhood.
- Advocate for respect for the sexuality of all women and girls.
- Adapt sex education programs to include girls and women with disabilities. For example, let blind women feel a condom and learn how to use one by touch. Use pictures and models to make learning easier for deaf women and women who have difficulty reading or understanding.
- Watch out for disabled girls and women, especially those whose disabilities affect their learning and understanding. They are often more vulnerable to sexual abuse. Women's safety is the whole community's responsibility. For more information about helping women who have been abused, see Chapter 14.

Train women with disabilities as health workers to provide sex education for other girls and women.



To the health worker:

Many women with disabilities have questions about sexuality. But they are often afraid or ashamed to ask. As a health worker, you can help by learning more about ways disabled women can be sexual and by talking with them about their concerns and hopes.

You can work together with disabled women to organize events or programs that reach out to women and girls who have disabilities. In one community, a group of young disabled women invites a health worker and woman's health doctor to participate in a yearly group conversation about sexual health. The women talk with one another and ask questions about sexuality and women's health.

You can also help girls and young women with disabilities get good information about how their bodies are changing. You can explain what it means to be a woman, and answer their questions about relationships and sexuality. As a health worker, you can work to change the beliefs and attitudes that make it harder for girls and women with disabilities to feel good about their bodies and sexuality.