Many parents of children with developmental disabilities often wonder whether they really need to talk with their children about sexuality. They may not think of their child as a sexual person because of their disability, or they may feel afraid that talking about the topic will spark their child’s interest in sex and cause them to start having sex. Planned Parenthood of Northern New England believes that it is vital for parents to talk about this topic with their children. Why? Because we are all sexual beings!

Even though the media in our culture present a narrow view of who is considered sexual, we really are all sexual beings. The media’s view would have us believe that only thin, blonde, strong, physically fit, tall, young, able bodied people are sexual. We need to remember that all people—including people with developmental disabilities—are sexual! People with developmental disabilities are often left out of the conversation about sexuality, but in reality, they, too, have thoughts, feelings and concerns about sexuality, just like everyone else.

While it is important to acknowledge that people with developmental disabilities are sexual and have thoughts, feelings and concerns about sexuality, it is also true that much of the information they receive is inaccurate. Because many adults are not willing to discuss these issues with them, many people with developmental disabilities get information about sexuality from television, which may be inaccurate or misleading.

This is another reason why it’s vital that parents talk with their children about sexuality—to explain information they’re getting using language that they can understand, and to be sure that the information that they are getting is accurate. In addition, sometimes messages about sexuality on television can be negative, and it’s important for parents to be able to give their children positive messages about sexuality, and help their children understand their own values about sexuality.

Another issue for people with developmental disabilities is that they may be very isolated or not have many friends. When they are

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isolated, they often miss out on the informal learning that happens while hanging out with friends. This is a way that many people have learned about sexuality. Friends often talk with each other about who they have a crush on, or how their bodies are changing as they're going through puberty. Sometimes these conversations happen at school, and sometimes they happen when they are with their friends outside of school. For people with developmental disabilities, they may not be in a school setting where informal learning takes place, and don’t have opportunities to hang out with friends to talk about these kinds of concerns.

Finally, an extremely important issue in sexuality education is prevention of sexual abuse. People with developmental disabilities are at risk of being sexually abused because they are frequently taught to comply with what others are asking them to do, and they often want to please others. By understanding various aspects of sexuality and relationships, parents can help their children understand what is healthy and what is not healthy, and that it's okay to say "no" to unwanted touch.

Even if parents think that sexuality education is important, there are lots of reasons that they don't talk about it with their children. They may not know how to begin or what to cover. They may know what to cover, but don't know how old their child should be before they start talking, or they may fear that talking about it will encourage their children to have sex. Or, parents may not even know what they believe regarding sexuality and their own children.

This newsletter is designed to help parents become aware of and overcome their own barriers to talking about sexuality with their children. The first article focuses on looking at our own values and attitudes and how they may help or hinder our child's sexual development. The second article will help parents figure out what topics to cover when. The third focuses on tips for talking about sexuality and how to make the conversation more comfortable. The third and fourth article are special topics: Sexual Abuse Prevention and Healthy Relationships. Sexual Abuse Prevention will explain how to talk with your child about what sexual abuse is, ways to prevent it, and what to do if it happens to your child. The Relationships article helps parents recognize that their child may be able to have a healthy sexual relationship.

Hopefully, this newsletter will help you clarify your own values around sexuality, and feel less fearful and more prepared in talking about sexuality with your own children. It may not give you all the answers, but it should help you get started. Ignorance may be bliss, but knowledge is power. Your children deserve and need that knowledge just like anyone else.
Our hope for our children is that they will be sexually healthy: that they will accept, appreciate and take care of their bodies; that they will have relationships that are enriching and not exploitative; that they will express themselves sexually in safe and pleasurable ways; that they will avoid unintended pregnancies, sexually transmitted infections, and abuse; that they will feel good about being male or female; and most importantly, that they will be who they really are.

Given this hope for sexual health, how do our values about sexuality help or hinder our children’s sexual development? Let’s take a look at what our values are about certain topics and how those values might impact our children.

Ask yourself the following questions:

What are my thoughts about masturbation? Sexual orientation? People with disabilities being in relationships or having children? After you have thought about these topics and feel that you are clear about your values surrounding these topics, think about how your values might help or hinder your child’s sexual development? Here are a few examples from parents of children with disabilities:

One parent said that she never ever thought her daughter would be in an intimate relationship. She never talked with her about sexuality and relationships because she had written off that part of her life. One day it dawned on her that she, herself, was the barrier to her daughter having the opportunity to be in a relationship, not her child’s disability. She realized that her daughter was capable of having a relationship, that she was holding her back. She saw that her values and beliefs were hindering her daughter’s future happiness.

One parent said that she didn’t want her child to masturbate because she was worried about him masturbating in public. This fear about masturbation and the value that people shouldn’t masturbate was changed one day when she learned that it was normal to masturbate and normal not to masturbate. She decided that she needed to help her child understand that it was okay as long as it was done in private.

Another parent felt that homosexuality was wrong. When her brother told her that he was gay, it changed her view of homosexuality and made her realize that anyone can be gay—including her own child. She needed to not assume her daughter was heterosexual and to be careful of the messages she was giving her daughter about homosexuality.

Another parent said he always answered his son’s questions about sexuality. He talked with him about everything from body changes to relationships. When his son expressed an interest in some day getting married, he listened and supported his son’s dream. A friend told him how impressed he was that he was so positive about his son’s sexuality. This made him realize that giving information about sexuality and supporting his child’s dreams had a strong, positive impact on his son.

These are situations where people learned more information and had some kind of experience that changed their thinking about their child or a particular topic. It’s important to be clear about your values with your child, but also to take time to look at your values and how they might be helping or hindering your child’s sexual development. We have a strong influence on our children, both negative and positive. Having a positive influence on our children can make a tremendous difference in a young person’s life.
Parents often feel more comfortable talking with their children about sexuality if they know what changes to expect as children develop and what to cover at each age. People with developmental disabilities develop physically at the same rate as people without disabilities. However, their social development may be delayed for many reasons. Their disability can affect how they relate to other people. They may not play with other children or they may always be around adults who watch them carefully. They may need physical assistance to move or play. They may also take longer to learn new things and develop language skills. Even so, sexuality education for people with developmental disabilities should include giving correct information, providing opportunities to develop values and attitudes about sexuality, and skill-building to practice sexually healthy behaviors.

Age 0-8: Young children tend to be curious about what their genitals are for and what they do. If they happen to see the genitals of someone of the other sex, they may also be curious about the physical differences between males and females. Depending on their language skills, young children will also learn names for genitals and may engage in "poopy talk" or the use of slang words. Children are also able to experience pleasurable feelings from their genitals beginning even before they are born, so it is very common for young children to touch their own genitals. This is a good time to teach that behaviors such as masturbation should be done in private, like alone in the bedroom or bathroom with the door closed.

During this period, it is also common and normal for children to engage in sex play with other children of about the same age. Children with developmental disabilities, however, may not have enough privacy or social interaction with other children to experience this. If sex play does take place, it is likely to be observed and ended by parents or other adults right away, and may be perceived to be abnormal or dangerous.

Young children also begin learning about expected behavior for males and females through family, toys, chores, books, and other media, and they may be curious about where babies come from.

What to teach:

- Accurate names for body parts and their functions
- That sexual body parts are private
- The distinction between public and private places
- Similarities and differences between boys and girls
- Body image - That bodies are different and good just the way they are
- People have the right to refuse touch from anyone at any time
- Masturbation can be pleasurable and should only be done in private
- If someone tries to touch your private body parts, say "no," leave, and tell an adult right away
- Where babies come from (in simple terms)
Age 9-13: At these ages, almost all children begin going through the changes of puberty. Therefore, children should be taught about what puberty means and what kinds of changes their bodies will go through.

Children with developmental disabilities should be taught about intercourse, reproduction, pregnancy, and birth. Depending on the extent of the disability, this discussion can be more or less detailed. It's a good idea to start out at a level that you know your child will understand, ask for feedback, and then add more information as your child wants it. No matter how much you explain, it is important to give accurate, concrete information. Although the story about the stork may be easier to explain, it could be very confusing and misleading for your child! There are a number of good books available for children that explain these issues, and you and your child can look through them together (they also give parents a good model to follow when talking with their children). Some of these books have pictures that explain about reproductive anatomy and physiology, intercourse, reproduction, pregnancy, and birth, if your child has limited language skills. (See page 12 for a list of resources)

Boys and girls should be taught about:

- Body changes:
  - Body hair
  - Menstruation - what it is and how to deal with it (girls may need more information on using and changing pads/tampons, what to do if it happens at school, etc.)
  - Breast development (some boys grow breast buds that go away in a year or so)
  - Vaginas lubricating
  - Penis and testicle growth
  - Erections and "wet dreams" - what they are and that they're normal
  - Hygiene - pimples, body odor, etc.
- Masturbation - what it is and that it should only be done in private
- Reproduction and pregnancy - what intercourse is, and that it is for consenting adults
- The changes of puberty happen at different rates for different people
- They have the right to refuse touch from anyone at any time
- Body image
- Gender roles and stereotypes

Age 14-20: Many children this age will continue to experience the changes of puberty by showing interest in dating and relationships, even if they don't feel ready to be in ones. Adolescents should learn that a good romantic relationship is a lot like a good friendship, except that both people are attracted to each other—they think about each other often, they want to spend time together, and they may want to kiss and touch each other's bodies.

Adolescents should also be taught that intercourse (oral, vaginal, or anal) can lead to pregnancy and sexually transmitted infections (STIs), but that people can reduce their risk by using birth control and condoms. They should also know that sexual feelings are normal and healthy, but that not all sexual feelings should be acted on. Some relationships may be inappropriate for them, such as relationships with people much older or younger than them. They should learn that their bodies belong to them, as well as how to say "no" to someone who is trying to pressure them into sexual activity. They also need to learn to who it is appropriate to hug, kiss, or touch, and how to make sure both people want to at the same time. On the other hand, adolescents with developmental disabilities should be given the opportunity to experiment with appropriate relationships and friendships.

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Tips for Talking About Sexuality
by Katherine McLaughlin

Many parents of children with developmental disabilities need help talking about sexuality. Here are some general tips for talking about this sensitive topic.

You may have to initiate. Many children won’t ask questions, so you may need to be the one to bring it up. This can be done by saying Now that you’re growing up, I want to talk with you about body changes," or, "Some people have many questions about sexuality, like how are babies made? Or will I ever find a partner? Or what is a condom? What questions do you have about these topics?"

Give age appropriate information. It’s important to talk with your child about the sexuality topics for their actual, biological age, not their cognitive age. For example, when a girl is 11 years old, it’s important that she learns about body changes to prepare her for puberty, even if her “cognitive” age is 5. The trick is finding ways to teach abstract concepts in ways that your child can understand.

Simplify your responses. When answering your child's questions, less is more. Begin with the simplest explanation and move to a more complicated one if your child continues to be interested or ask questions.

Be patient. Concepts will need to be covered more than once. Skills will probably not be learned after one discussion or practice session. Expect children to ask the same questions again and again.

Find ways to be concrete when teaching the topic. Use anatomically correct dolls, three-dimensional models, drawings, photographs, and videos.

Try to give a consistent message. It can be confusing for children with developmental disabilities when their parents give one message and a provider gives another message. Work closely with the people in your child's life to establish and give consistent, positive messages about sexuality.

Try not to react. If your child is doing something inappropriate or asks a shocking question, try not to react. Try to remain calm. Respond to the behavior, by naming it and telling them what is appropriate to do. Answer the question in a matter-of-fact way. How you respond sends a message about sexuality and tells your child whether you are an "askable" parent.

Provide for practice in a safe setting. Some skills may be easy to break down into smaller steps, while others will present a greater challenge. For example, it may be fairly easy to teach a young adult how to use a condom correctly, but it may be much harder teaching a young adult how to ask a partner to use a condom and what to do if the partner refuses. Role playing is a method for practicing these skills--you pretend you’re the partner, and your child brings up using condoms. It gives them practice at responding to their partner's reactions.

There's nothing wrong with being embarrassed, and there's nothing wrong with telling your children that you're embarrassed. This helps to make it clear to your child that the embarrassment belongs to you and not to them or the topic. You may even explain that your parents didn’t talk with you much, if that is the case, and that’s why you feel embarrassed.
Let a book say the embarrassing stuff. That way, you and your child are a team, confronting and reacting to all of the embarrassing things being said in the book. (See Resource Section on page 12)

You don't need to know the answer to every question. If you don't know an answer, you and your child can hunt for it together. Make use of local resources -- libraries, doctors, nurses, Planned Parenthood Health Centers, etc.

If you're thrown by a question, you have the right to answer it later. Sometimes children pose questions that we'd like to answer, but we may be so taken aback that we don't know quite how to respond. It's perfectly okay to say, "I'd like to answer that question, but first I need to think about what I want to say." Just make sure you answer the question later.

You have the right to pass on personal questions. One way to help children develop their own privacy standards is for them to see that you also have your limits.

Watch your body language. Your words and body language should be giving the same messages. Don't grimace when you're saying, "What a great question!"

Each time you respond in a way that helps your child learn concretely and positively, it will get easier for you. Try imagining the hardest question your child could throw your way and practice answering it.

Let your children "overhear" conversations. Your child may be too embarrassed to discuss sexual topics, but they may not mind hearing a discussion about the topic.

Ask your child for their opinion. Their self-respect begins with the consideration they receive from others.

Have a back-up person for your child. Ideally, we want our kids to talk with us, but they may be uncomfortable and need another option. Find someone that has similar values to yours that your child can go to if they have a question or a concern.

These tips will help you have successful conversations with your child about sexuality. And remember, these conversations are not one-time-only talks. Keeping the lines of communication open will help your child learn, and will help you feel more comfortable talking.

Adolescents should be taught about:

- Reproduction, pregnancy, and birth
- Sexually transmitted infections (STIs)
- Birth control and condom use
- How to say "no" to unwanted sexual contact
- Respecting personal space
- Romantic relationships and friendships
- Body image
- Gender roles and stereotypes

In summary, certain ideas and skills should be taught early and often, such as the difference between public and private places, different kinds of relationships and appropriate behavior within those relationships, and body rights. You will have many opportunities to teach about these things! Remember that much of sexuality education for people with developmental disabilities is about taking advantage of "teachable moments." In fact, using teachable moments is the most concrete way to help your child learn about sexuality. The most important thing is to talk. Your child needs this information just as much as any child!
One of the greatest fears parents of children with developmental disabilities have is that their child will be sexually abused. This fear comes from hearing that 50-90% of people with developmental disabilities will be sexually abused at some point in their lives, and that 99% of the abuse is from someone they know. The fear also comes from our knowledge that people with developmental disabilities are vulnerable to abuse because they want to please and comply with others’ wishes. Sometimes having these fears makes us want to keep our children close by in order to prevent sexual abuse from happening. In reality, a more effective way to prevent sexual abuse is to help children recognize sexual abuse and give them the skills to stop it.

When talking with our children about sexual abuse we need to tell them that:

Everyone has “private parts.” The private parts for boys are penis, testicles, and buttocks. The private parts for girls are vulva, vagina, breasts, and buttocks.

You get to decide who touches your entire body, including private parts. It is your body.

It is never okay for someone to touch your “private parts” or ask you to touch their “private parts” especially when they tell you to keep it a secret. A secret is when the person doesn’t want you to ever tell anyone else. The only times that it is okay for someone to touch your private parts is when they are helping you bathe and you need that help (and feel comfortable with them), when a doctor or nurse is doing an exam to make sure you are healthy, or when you are in a romantic/sexual relationship with someone and you have both said “yes” to touching each others bodies and private parts. Other types of sexual abuse are someone showing you their private parts, asking you to watch sexual movies with them, or trying to take a shower with you.

When you get older, you might meet a special person that you really, really like and think about all the time. The two of you may decide to start a romantic/sexual relationship. When you meet that person and get to know them, then you may be ready for them to touch your body and private parts. That is not sexual abuse; that is what some people choose to do in a romantic/sexual relationship. Ask your child who they know that are in a romantic/sexual relationship, and talk with him or her about what makes that relationship romantic/sexual.

Sometimes when a person sexually abuses someone, it can feel good. Even though it isn’t okay, it can still feel good. Just because it feels good doesn’t mean that it’s okay it happened.

Usually people are sexually abused by someone they know—a family member, neighbor, babysitter, camp counselor, care provider, personal care attendant, clergy person, teacher, bus driver, or staff person. Most people will not sexually abuse someone, but it’s important to know what sexual abuse is so you can protect yourself. Many times these people are very nice so you may think the behavior is okay. Or you might be afraid that you are being mean if you tell on them. This might make it difficult to tell someone you trust what has happened or is happening. Also, they may tell you not to tell or something bad will happen. It’s still important to tell, even if you went somewhere that you weren’t supposed to go or did something you weren’t supposed to do. The person that did this to you needs help and telling will get them that help.

Besides telling your child about sexual abuse, it’s important to give them the skills to say “no.”

This skill can be learned when he or she is very young, or in situations that are less risky than a sexual abuse situation. For example, ask your child what she wants to wear today. After she decides, say, “That’s great. It’s your body and you get to decide.” Each day, you can add a little more pressure to your question when you ask what she would like to wear. You can say, “I...
know better than you, I'm older," or, "You're wrong, I think you should wear the green shirt." If she gives in, which she may do, tell her, "It's your body and you get to decide what to wear." There are many opportunities in our kids lives where we can let them decide for themselves and support that with praise.

Once you feel they are getting the idea that they can say "no" and it is their body, you can practice using a scenario about sexual abuse. Tell your child about a situation where a neighbor asks a child to come into his house. The child goes in, and the neighbor asks, "Can I touch your private parts, or will you touch mine?" Ask your child what he would do if this happened to him. If your child says, "I would say okay," tell him that he does not have to do that. If he says, "I would say no," your next response could be, "What if the neighbor said, ‘Okay, we don't have to do that, but don't tell anyone that I asked you, okay?’" Then you could ask your child what he would do in this situation. See if your child says whether he will tell or not. A great way to remind your child of what to do is to tell him to say "No," get away, and tell an adult. And if the adult doesn't believe you, keep telling them or tell someone else.

We can also impact our kids by explaining the difference between being polite and complying. Sometimes we want our children to act a certain way. We may want them to kiss a family member. It is very important that we let our kids decide for themselves if they want to kiss or touch a person in a certain way. If we say, "Kiss Sarah goodbye, show her you love her," we are teaching our kids that they should touch a certain way and comply to unwanted touch. If the child says, "I don't want to," we need to respect that. If we keep pushing and say, "You hurt her feelings," it sends a message that how they feel doesn't matter; what matters is not hurting other people's feelings. If your child is being abused, the person doing the abusing can say, "I want you to touch me and it hurts me when you don't." We need them to get the message that it's their body and they get to decide who touches them. Another way to address touch is to ask your child how they would like to say "goodbye" to Judy. Do they want to say goodbye, hug them, kiss them, and wave to them? If their choice involves touching another, it's good to teach your child to ask first. It just reinforces that we need to respect others' wishes about touch just as others need to respect ours.

Giving our kids privacy can also teach about sexual abuse prevention. If we are responsible for bathing our kids, it's important to give them privacy around that situation. An example would be setting up a lower shower curtain so you can assist, but part of their body is covered. It gives them privacy and demonstrates respect of their need for privacy.

But giving privacy is only one part of it. We also need to be a good role models around respecting privacy. If we talk about these skills and then don't do them, we send a different message. Do you ask them before you touch them or help them bathe? We can't say, "You need to ask before touching someone" and then touch them without permission. We can't say, "People need privacy" and then walk in the bathroom without asking. We can also model how to speak up for ourselves by telling a person that you don't like certain touch when it happens to you. We need to model all that we teach.

Part of sexuality education is learning the medical terminology for genitals. It's good to have that because it sends a positive message that all parts of your body and important and not something to be ashamed of, but also would be helpful if your child is sexually abused. If your child tells that someone tried to touch their "cookie," people won't understand what they mean. If your child says, "Someone tried to touch my penis or vulva/
Many parents of people with developmental disabilities think that their child will never have a successful romantic relationship. Parents often worry that their children will be rejected or taken advantage of. They also worry that their children will get pregnant (or get their partner pregnant), or get a sexually transmitted infection (STI). It can be hard for parents to let themselves dream of their child in a healthy sexual or romantic relationship because it seems like such a long shot. Sometimes parents try to protect their children by preventing them from having sexual or romantic relationships. When this happens, people with developmental disabilities may only have relationships with family members, direct care staff, and possibly a few other friends. These relationships are very important, but a relationship with a partner can make a person feel good in a unique way. A romantic relationship can allow two people to take care of each other and feel close to each other. Many people think that romantic relationships are very different for people with developmental disabilities, but they're not. In her book, Couples With Intellectual Disabilities Talk about Living and Loving, Karin Melberg Schwier interviews couples with developmental disabilities about their relationships. Michael Creamer, 27, says of his girlfriend, Patsy, 25, "When Patsy and I go out on a date, we talk. We walk around the park most often. We ate together. We once were little kids. Little buddies together. Then we grow up and she makes me so proud. Her for me and she is happy. Patsy is a good personality. If someone tell me I can't have her, can't have a girlfriend, would explain most often love I feel for her, comes back to me from her. That's all." Debbie, 18, describes her future wedding with boyfriend, Josh, 19, "And I would say I want to go out with him. And I would say I love him and I want to be with him and I want him as my boyfriend. If Joe McIntyre [of the musical group, New Kids on the Block] shows up I would tell him too bad, I am marry now." It is easy to see that these young people's feelings about their relationships are no different than the feelings of people who are not disabled. They enjoy spending time together and dream about their futures with each other. Most importantly, their relationships allow them to feel close to someone of their own choosing.

Parents can increase the chances of their developmentally disabled children engaging in healthy intimate relationships by keeping several things in mind:

Understand that your child, despite her/his disability, is a sexual being with the same desires and needs as the non-disabled. Most likely, your child will need some help finding an appropriate relationship, but she still has the right to express herself sexually with someone who wants the same kind of relationship.

The more chances a person has to meet others with similar backgrounds and interests, the more likely s/he will establish a relationship with someone. Therefore, it is important to provide social outlets for your child where he can explore
different relationships and choose ones that feel good.

Remember that she will probably have the same kinds of problems that non-disabled people do when trying to find the right relationship. We all make mistakes in this area, but as a parent of a person with developmental disabilities, you can help your child learn from these experiences by talking with her about what is happening, how she feels, and offering advice about what to do.

Teaching your child about sexuality issues, including body parts, private and public behavior, sexual abuse prevention, and pregnancy and sexually transmitted infection prevention, can help prepare her/him to have a safe and healthy relationship. There are resources available to help you talk about these subjects with your child at his level of understanding.

It is natural to want to keep your child safe from harm, but it is also important to allow her/him to experience the joys and challenges of being intimate with someone that s/he chooses.

"vagina," people will clearly understand what that means and will be less likely to ignore what the child has said.

Many people wonder what to do if their child tells them that they were sexually abused. First, believe them. You don't have to decide if it's abuse or not. People are trained to investigate and figure that out. An important message to tell them is it is never their fault and that you are really glad that they told you.

Making sure our children have sexuality education helps prevent sexual abuse because it shows what healthy relationships are. It can help them realize when something isn't quite right.

Preventing Sexual Abuse of Others

The other side of sexual abuse is that many times people with developmental disabilities are accused of sexually abusing another person. Many times this is about not understanding what is okay touch. Perhaps they themselves were sexually abused and figured it was normal to touch others without asking. We need to teach our children when it is okay to touch another person's "private parts."

It is okay when:

You are in a romantic/sexual relationship with someone and you have both said "yes" to the touch without being pressured and you are in a private place. A private place is alone with the door closed, where people don't come in. You can talk about what you think is important to have in a sexual/romantic relationship and have your child talk about it too.

It is never okay to touch someone's private parts when:

The person is a child. You can ask your child to name a few children that they know.

The person has said "NO."

The person is your mother, father, brother, sister, aunt, uncle, cousin, or step-parent. You can ask your child who are our family members? You can also explain someone's husband, wife, or partner may be in a romantic/sexual relationship and be in the same family. You can say that they were in different families and because of their sexual/romantic relationship, have become family members. That is the only time people in a family touch each other's private parts.

There are many ways to help our children from being sexual abused. Some may seem hard and others easy, but what's most important is that the more our children know about what sexual abuse is and how to stop it, the more equipped they are when they face a serious situation. We can't stop all pain from reaching our children, but we can try our best to help them be safe as they live in our communities.
Resources

Books


Sexuality: Your Sons and Daughters with Intellectual Disabilities. Karin Melberg Schwier and David Hingsburger. Publisher


Websites

www.ppnne.org
www.nichcy.org
www.diverse-city.com
www.siecus.org
www.teenwire.org
www.sexualhealth.com
www.plannedparenthood.org
www.yai.org
www.qualitymall.org

Videos


