

OUR RIGHTS  
**RIGHT**

**NOW!**



---

# A GUIDE FOR PARENTS AND GUARDIANS

---

Illinois Imagines Project  
July 2013

# Table of Contents

Facilitator’s Guide for A Guide for Parents and Guardians .....	1-10
A Guide for Parents and Guardians .....	1-50

---

*This project was supported by Grant #2011-FW-AX-K010 awarded by the Office on Violence Against Women, United States Department of Justice. The opinion, finding, conclusion and recommendation expressed in this program are those of the author(s) and do not necessarily reflect the views of the Department of Justice, Office on Violence Against Women.*

## ACKNOWLEDGMENTS

Thanks to the Illinois Imagines Team members, who worked creatively and collaboratively to envision and create new ways to serve women with disabilities who experience sexual violence. The Illinois Imagines team includes:

- Self advocates
- Department of Human Services, Division of Community Health and Prevention
- Department of Human Services, Division of Rehabilitation Services
- Department of Human Services, Division of Mental Health
- Department of Human Services, Division of Developmental Disabilities
- Illinois Coalition Against Sexual Assault
- Illinois Family Violence Coordinating Council
- Illinois Network of Centers for Independent Living
- Blue Tower Training

We owe a great debt to all of the women with disabilities and community teams who participate in this project. They contribute countless time and energy to every aspect of Illinois Imagines. Along the way, they give us invaluable insight into their world, sharing their thoughts, feelings, ideas and dreams. Without their guidance, we could not have done our job.

Special thanks to Pam Myo, Shirley Paceley, Mary Suggs, Teresa Tudor and Suzy Woods for writing the material that went into this module; Carol Corgan for editing and writing material, and; Sean Black for editing and layout of this module.

# FACILITATOR'S GUIDE

ILLINOIS IMAGINES  
OUR RIGHTS  
**RIGHT NOW!**



## FACILITATOR MATERIALS

The *Guide for Parents and Guardians* is a tool for parents and guardians of women with disabilities regarding healthy sexuality and sexual violence prevention. The goal of this *Guide* is to engage, inform and empower parents and guardians to participate in and support sexual violence prevention in their child's life. The *Guide* is intended for use by parents and guardians on their own or alongside a prevention education program or session conducted by an agency like yours. Other family members and significant others may also find this *Guide* useful.

As a service provider from a disability service agency or a rape crisis center, you are in an ideal position to implement this *Guide* with parents and guardians. You can provide education about the *Guide*, answer questions and be a role model for how they can engage with their child about healthy sexuality and sexual violence prevention.

**If you are using *Our Rights, Right Now* from the Illinois Imagines Tool Kit, this guide is a great accompaniment to the module entitled “Women with Disabilities and Sexual Violence Education Guide.”** As you begin to conduct education sessions with women with disabilities, sharing information with parents and guardians is essential. This may occur in an information session, individual conversations or correspondence with parents and guardians. Ideally you will schedule an education session with parents/guardians. However this communication occurs, be aware that engaging parents and guardians is key. Parents and guardians need to know how to reinforce the sexual violence prevention education that is provided to women with disabilities. They are central role models, teachers and responders to their child's needs, and you can support them in those roles.

**For more information on the Illinois Imagines project please contact Teresa Tudor at [Teresa.Tudor@illinois.gov](mailto:Teresa.Tudor@illinois.gov) or visit [www.illinoisimagines.org](http://www.illinoisimagines.org).**

## How to Use the Guide for Parents and Guardians

Read the *Guide* so that you are familiar with the information being provided to parents and guardians. Be prepared to discuss the material in the *Guide* with parents/guardians during formal and informal interactions. Let the *Guide* be the foundation for your education with parents and guardians. The facilitator's material is for you to use as needed in support of your work with parents and guardians.

As you facilitate parent/guardian engagement and education, the five documents listed below can help you navigate your work with parents and guardians.

- Supporting Parents/Guardians in Sexual Violence Prevention (pg. 3)
- Educational Session for Parents/Guardians/Family Members (pgs. 3-6)
- Sample Letter to Parents/Guardians (pg. 8)
- When a Parent or Guardian Says “No” to Prevention (pg. 9)
- Supporting a Parent/Guardian after Disclosure of Abuse (pg. 10)

## SUPPORTING PARENTS/GUARDIANS IN SEXUAL VIOLENCE PREVENTION

All people need education about healthy sexuality and sexual violence in order to be knowledgeable and safe. This is particularly true for women with disabilities, who face a greater risk for sexual violence than those without a disability. Parents/guardians need to be supported in providing this information and in responding to their child in the event of sexual violence.

### Education Sessions with Parents/Guardians

It is useful to plan and conduct sexual violence prevention education sessions for parents/guardians of people with disabilities. Such a session is an opportunity to discuss any upcoming prevention programs being conducted with women with disabilities. The outline on the following pages is a good place to start. It guides you through a one hour session and provides an introduction to the issues of healthy sexuality and sexual violence in the lives of women with disabilities. The “Letter to Parents/Guardians” on page 8 can be used to invite parents to the education session and inform them about upcoming prevention sessions with women with disabilities.

### Tips to Support Parents/Guardians

**Reinforce** the need for education about healthy sexuality as a foundation for sexual violence prevention.

**Help** parents/guardians find all the information they need to talk about healthy sexuality with their child. Direct them to the *Guide for Parents and Guardians*.

**Encourage** the parent/guardian to talk with community disability agencies about how to approach sexual violence prevention with the people they love.

**Tell** the parent/guardian that the local rape crisis center provides sexual assault prevention education and is a good resource for information about sexual assault and sexual assault prevention.

# Educational Session with Parents/Guardians/Family Members Agenda

## Presenters

Ideally an educator from a disability agency or rape crisis center **and** a self advocate should present this session.

## Time

This session will take approximately one hour. If you have more time, provide a more in-depth review of this guide.

## Materials

- Copies of *Guide for Parents/Guardians*
- Handout – Read-around slips (page 6)
- Flip chart and markers
- Highlighters/post-its for participants
- Brochure from rape crisis center and disability service agency
- Your business card

## Agenda

### 1. Welcome, Introductions and Opening Activity – 10 minutes

After introducing yourself and facilitating introductions of the participants, acknowledge that parents/guardians in the audience certainly must have concerns and fears regarding sexuality and sexual abuse in the lives of their loved ones with disabilities. Ask volunteers to “shout out” their top concern/fear in this area. Record on flip chart as people speak. After you have a list, go through it and ask people to raise their hand if they share this concern/fear. Normalize their concerns and state that is why this project exists: to help all of us grapple with our fears in order to enhance the sexual safety of women with disabilities.

### 2. Read-Around Activity – Time needed: 5 minutes

Before the session, cut out the read-around slips on page 7 to pass out to the participants. Tell the group these are actual statements from women with disabilities in focus groups answering the question: What do you want people to know about you and your sexuality?



Ask for volunteers to take a read-around slip to read aloud to the group. Ask for silence while the statements are read, with no comments or questions. Instruct readers to pause for a count of five seconds between the reading of the statements.

After the statements are read, let the group sit silently with their reactions for a moment. Then ask if anyone would like to share their reactions. An alternative is to ask participants to write their reactions, which could or could not be shared with the group.

### **3. Distribute the *Guide for Parents and Guardians* – 5 minutes**

Pass out copies of the *Guide for Parents and Guardians*.

Review Section 1, including What you Will Find in This Guide and Terminology.

Tell the audience you will be highlighting segments of the *Guide*. Note there is not time to review all the material and that you hope they will make time to read it in the coming weeks.

Pass out highlighters/post-its for the audience to use while reviewing the *Guide*. Tell them this *Guide* is theirs and they can note pages or items they want to remember or find quickly.

### **4. Why Teach My Child about Sex? – 5 minutes**

Direct audience to this lesson. (page 5) Note that silence on the subject has not yet protected women with disabilities.

Move on to the next page in this section (page 6) Note that education can reduce risk. Review the list of positive outcomes of sexuality education.

### **5. Sexuality Education is Risk Reduction? – 10 minutes**

Move to “Sexuality Education is Risk Recuction” (page 6) Tell parents/guardians they can ask for prevention programs from local disability service agencies and rape crisis centers.

Go to “Key Messages in Sexuality Education with Women with Disabilities.” (page 7) Review why it is important and ways parents/guardians can participate in prevention education.

### 6. So what's this Program My Child is Going to Learn About? – 10 minutes

Move on to the *Our Rights, Right Now*. (page 27)

Tell the parents/guardians that this section of the *Guide* summarizes the prevention program that their child is invited to attend. Note that the *Our Rights, Right Now* prevention curriculum has four topic areas:

- **Healthy Relationships – 5 lessons**
- **Healthy Sexuality – 4 lessons**
- **Sexual Violence Risk Reduction – 5 lessons**
- **Safety and Support: How to Get Help – 5 lessons**

If you know, tell the parents/guardians which of these lessons will be taught to their child. If you don't know this, tell them that the sessions their child will attend may address some or all of the topic areas, depending on time available. Note that all of these lessons can be taught and reinforced at home, using the *Guide for Parents and Guardians*.

### 7. What if My Child is Abused? – 10 minutes

Refer the parents/guardians to “Responding to Sexual Violence.” (page 37) Tell them this section has information that can help them if their child experiences sexual violence. Tell the audience that a disclosure of sexual violence may be about a recent incident, one long past, or both. The same information applies regardless of timing. Note that the chapter describes:

- Indicators of abuse.
- How to respond to a disclosure.
- Self care.

### 8. Closing – 5 minutes

Thank the audience for their time. Offer to answer any additional questions. If possible, note you will be available after the session for more discussion, if desired. Give the audience:

- Your business card;
- Brochure or other information about local rape crisis center;
- Brochure or other information about local disability service agencies.

READ AROUND ACTIVITY

-----

I am a human being, just like everyone else.

-----

I am a sexual being, just like everyone else.

-----

I am not a child; I am an adult.

-----

My sexuality is a human right, not a legal one.

-----

I have the right to information, community participation, private sexual expression, boundaries in personal care and relationships, and a full life.

-----

## SAMPLE LETTER TO PARENTS/GUARDIANS

Dear Parent and/or Guardian,

As part of our health education services, we are partnering with a rape crisis center to provide education regarding healthy sexuality and sexual violence prevention. As you know, health education is an important curriculum area for all individuals, and it may be even more important for people with disabilities who face increased risk for sexual violence. The program includes a total of # sessions and will be conducted frequency beginning date.

An education session for parents/guardians is scheduled for date/time/place. We hope you can attend to learn more about this program. If you cannot attend but want more information about this education program please contact name and contact information.

While education about sexuality is often an uncomfortable subject for parents/guardians to approach, it is a necessary one from both an educational and safety perspective. Families are the best teachers. It is for this reason that agency/agencies name looks forward to partnering with you to provide this type of education and support to you in this area of your son/daughter's life.

As people with disabilities have more opportunities to develop relationships with others and interact in a variety of settings in the community (job, school, social activities), it is essential that sexual violence education become a part of each individual's learning. For some individuals, this knowledge will help them make better decisions about relationships as well as decisions about sexuality. It will also empower them to speak up against abuse and seek help if they are abused.

This material will also inform parents/guardians about indicators of abuse and prepare them to respond in a sensitive, victim-centered way.

If you have concerns about this prevention education, please call me at phone #.

Sincerely,

Name

Agency

## WHEN A PARENT OR GUARDIAN SAYS “NO” TO PREVENTION

Staff members at disability service agencies and sexual assault centers often ask, “What can I do when a parent or guardian says ‘no’ to having their loved one participate in educational or counseling programs?” Illinois Imagines provides the following guidance for talking with reluctant parents/guardians. Many situations and family dynamics influence these decisions, and it can be useful to learn more, provide more information and work with the parent/guardian to resolve their concerns.

### Step One: Find out what is behind the “no”

When a parent or guardian says, “I do not want my daughter in that class,” you might ask, “What are your concerns? Listen closely to the response.

### Step Two: Try to understand the concern

Concerned parents/guardians will have a range of answers to this question about their concerns. Your first response is to understand, so repeat back what you hear or believe the concern to be. Then listen again.

### Step Three: Provide empathy and factual information

Demonstrate concern for the individual and the parent/guardian’s concern while providing factual information.

### Examples:

**Parent/Guardian Concern:** “If she goes to that class (healthy sexuality), she will want to have sex. It is best we don’t open that door.”

**Facilitator Response:** “I understand you have concerns about Sue having sex, it can be scary. We have discovered that most people with disabilities already know some things about sex but much of their information is incorrect. When people don’t have correct information, they are more likely to be sexually abused or to be hurt in some other way. I would be happy to share the curriculum with you.”

**Parent/Guardian Concern:** “I am concerned that she will remember her abuse from years ago. She had a horrible time for years and she is doing better now. I don’t want all of that to start over again.”

**Facilitator Response:** “I am so sorry that Judy had to go through that. It must have been difficult for both of you. We have found that when survivors of sexual assault take these classes, they often feel much stronger and better able to stand up for themselves. What if we see if Judy wants to try the class and she can drop out at any time if she chooses?”

### SUPPORTING A PARENT/GUARDIAN AFTER DISCLOSURE OF ABUSE

When someone discloses an experience of sexual abuse, parents/guardians and other loved ones have a range of reactions. Often, they need support and information to process their emotional response. Working with parents/guardians of those with a disability, is the same as supporting any other parent/guardian.

Be prepared to discuss medical and criminal justice responses, the response of the disability service agency, rape crisis center services. Additionally, remember to inform and reassure the parent/guardian regarding the following key issue areas.

- The parent/guardian needs to believe their child and report the abuse to caregivers and others who can investigate what happened.
- Emphasize that the child is not to blame for the abuse. Reassure the parent/guardian that they also are not to blame. Remind the parent/guardian that the abuser is the only person responsible for the abuse.
- Explain to the parent/guardian that anger, depression, sexualized behavior, and/or shame are normal reactions to sexual abuse. Talk with them about how to cope with their child's reactions to the abuse.
- Encourage the parent/guardian to keep a journal. Explain that this may help them verbalize their thoughts and feelings.
- Tell the parent/guardian about the local rape crisis center, and encourage them to contact the center for information and support for their child and themselves.
- Strategize with the parent/guardian regarding how they can care for themselves. Remind them that their child needs them more than ever. They may feel angry or upset that their child did not tell them sooner or embarrassed that this happened to someone in their family. Tell them these are normal feelings that they may wish to share with a rape crisis center counselor. Remind them that it is important for them to find support in order to support their child.

# A GUIDE FOR PARENTS AND GUARDIANS

ILLINOIS IMAGINES  
OUR RIGHTS  
**RIGHT NOW!**



# A Guide for Parents and Guardians

Section 1: Overview: Women with Disabilities, Sexuality and Sexual Violence .....	3-12
Section 2: Prepare Yourself: Supporting Sexuality and Sexual Violence Prevention Education for Your Loved One with a Disability .....	13-20
Section 3: Sexual Violence Prevention .....	21-26
Section 4: Our Rights, Right Now: Women with Disabilities and Sexual Violence Education .....	27-36
Section 5: Responding to Sexual Violence .....	37-42
Section 6: Resources for Parents and Guardians ....	43-50



## THE PURPOSE OF THIS GUIDE

Parents and guardians are key to the work of preventing sexual violence against women with disabilities. As a parent or guardian, you are in an ideal position to educate and support the education of loved ones in relation to healthy sexuality, sexual rights and sexual violence, and safety planning. You are also likely to be the first responder to women with disabilities who experience sexual violence.

### **This guide will help you, as a parent or guardian:**

- Be aware of basic information about women with disabilities and healthy sexuality.
- Understand the sexual rights of women with disabilities.
- Be aware of risks and needs of women with disabilities in relation to sexual violence.
- Support and supplement education for women with disabilities regarding sexual violence, healthy relationships, healthy sexuality and sexual violence risk reduction.

## Terminology

The following words/phrases are used throughout this guide. Below are descriptions of what each word/phrase means in context to the material presented.

**Child** – The word child throughout this module refers to the person with a disability who is cared for by a parent or guardian. The term refers to any offspring/dependent with a disability. The term refers to the relationship, not the capacity of the person with a disability. Loved one, person and individual are used interchangeably with child.

**Parent/Guardian** – The person with a legal relationship with a person with a disability.

**Sexual Violence** – The term sexual violence is used throughout this module to refer to any act (verbal and/or physical), which is non-consensual and is sexual in nature. The term “sexual violence” includes sexual harassment, exposure, voyeurism, sexual abuse, sexual assault and other forms of sexual exploitation. Sexual violence may be perpetrated by a family member, partner, acquaintance, caregiver or stranger.

**She** – This module focuses on women, the most common victims of rape. The sexual assault victim is referred to as “she” throughout this module. However, men can also be victims of sexual violence. The reactions, feelings and needs of sexual assault victims, whether male or female, are very similar. The information in this module is equally relevant and helpful to male sexual assault victims and their friends and family.

**Victim/Survivor** – The terms victim and survivor are often used interchangeably, though individuals who are sexually victimized may prefer one term over another. Both terms will be used throughout this module. When working with a victim/survivor, ask her which term she prefers and use that term.

**Women with Disabilities** – This module focuses exclusively on women with disabilities, as this was the purpose and restriction of the funding. However, the material also applies to males and youth with disabilities who experience sexual violence.

# SECTION 1

# OVERVIEW — WOMEN WITH DISABILITIES, SEXUALITY AND SEXUAL VIOLENCE

ILLINOIS IMAGINES  
OUR RIGHTS  
**RIGHT NOW!**



## OVERVIEW

### WOMEN WITH DISABILITIES AND SEXUALITY

Human sexuality is as unique as each human being and develops in relation to many individual, physical, cultural and social factors. All people have sexual feelings and experience sexual changes across their life span. For many people, coming to fully appreciate their sexuality can be quite a journey. For women with disabilities, the journey can be treacherous.

Women with disabilities have often been deprived of information about relationships and human sexuality. Further, they have frequently been denied the right to sexual expression and/or privacy to engage in sexual behavior alone or with a partner. Finally, few women with disabilities receive information about sexual abuse, sexual assault and other forms of sexual violence. This lack of information and experience increases the risk that women with disabilities will experience sexual violence.

### WOMEN WITH DISABILITIES AND SEXUAL VIOLENCE

Women with disabilities experience sexual violence at a greater rate than those without a disability. They are also less likely than other women to identify abuse and seek services from rape crisis centers and others. One of the factors that contributes to the increased risk faced by women with disabilities is the lack of information and education they receive on issues related to healthy relationships, sexuality, sexual violence prevention and body safety.

Risk reduction is a key tenet of sexual violence prevention education. Though stopping the behavior of perpetrators is the only sure way to prevent sexual violence, women can take steps to reduce their risk of sexual violence. However, it is critical to remember, and to tell all women, that sexual violence is not their fault. No matter what they did or did not do, the behavior of forcing sexual contact is always the fault of the perpetrator, not the victim. Keeping that fundamental principle at the forefront, we can provide education about relationships and sexuality geared toward reducing the risk of sexual violence. Women with disabilities need this education as much as all other women and girls.

Women with disabilities face a greater risk of sexual violence than the general population. Please note the following facts about women with disabilities and sexual violence.

---

Among adults who are developmentally disabled, as many as 83% of the females and 32% of the males are the victims of sexual assault. (*Johnson, I., Sigler, R. 2000. "Forced Sexual Intercourse Among Intimates," Journal of Interpersonal Violence. 15 (1).*)

---

Women with disabilities and Deaf women are at similar or increased risk for abuse compared to women without disabilities. (*Brownridge, 2006; Martin et.al., 2006; Nosek et. al., 2001; Powers et. al., 2002*).

---

Women with disabilities experience increased severity of violence (*Brownridge, 2006; Nannini, 2006; Smith, 2008*), have multiple forms of violence, including disability-targeted violence (*Curry, et. al. 2003; Martin, et.al., 2006*), and experience the violence for longer periods of time (*Nosek, et. al., 2001*).

---

The social context of disability and Deafness increases a woman's risk for victimization. This context includes:

- reliance on support services,
- poverty,
- inaccessibility and isolation,
- devaluation and stigma
- discrimination

(*Powers, et. al. 2002; Saxton et. al., 2001*).

---

Potential consequence of abuse include negative financial, physical and social effects, such as:

- difficulty seeking or maintaining employment,
- increased depression,
- low self-esteem, mental health concerns,
- increased poor health, loss of independence

(*Hughes et.al., 2001; Nosek et. al., 2003; Nosek, et. al., 2006*).

---

Dependence on the perpetrator for personal assistance adds to the cost and complexity of the survivor/perpetrator relationship (*Copel, 2006*).

## WHY TEACH MY CHILD ABOUT SEX?

As parents and guardians perhaps your greatest responsibility is to listen to the words of women with disabilities. When Illinois Imagines asked women with disabilities what they want everyone to know about them and their sexuality, they indicated the following:

- I am a human being, just like everyone else;
- I am a sexual being, just like everyone else;
- I am not a child; I am an adult;
- My sexuality is a human right, not a legal one; and
- I have the right to information, community participation, private sexual expression, boundaries in personal care and relationships, and a full life.

Women with disabilities need education about sexuality and sexual violence in order to reduce their risk of being victimized. To achieve this, parents and guardians can:

- Provide facts;
- Create a safe place for expression;
- Accept their family member with a disability as a human being with rights and possibilities;
- Empower their family member with a disability to make choices and use her voice on her own behalf; and
- Support their family member with a disability in recognizing and totally embracing herself as capable, strong, sexual, and beautiful.

### SEXUALITY EDUCATION IS RISK REDUCTION

Women with disabilities need information about sexuality and sexual violence in order to reduce their risk of sexual violence and to get help if they experience sexual violence.

The belief that people with disabilities are not or should not be sexual leads to a denial of appropriate education. Special education students are often denied sex education and even violence education classes. Similarly, women with disabilities are often denied exposure to social experiences that could provide opportunities for learning and experimenting with relationships and sexuality. Some women with disabilities have not even had preventive gynecological exams. When education and experience are denied, women with disabilities lack the tools to understand their sexuality and are not empowered to respond to sexual violence.

Providing sexuality education for women with disabilities has many positive outcomes such as:

- Healthier choices
- Increased social skills
- Improved assertiveness
- Greater independence
- Increased ability to take responsibility for sexual behavior
- More appropriate expressions of sexuality
- Less chance of risk-taking behaviors
- Reduced risk of sexual abuse, sexually transmissible infections and unintended pregnancy
- Increased communication by women with disabilities about sexuality, including interests, desires, concerns, fears and experiences of sexual violence  
Increased safety

## KEY MESSAGES IN SEXUALITY EDUCATION WITH WOMEN WITH DISABILITIES

### Sexuality

All women are sexual, and they may express their sexuality in various ways. Talking about sex does not encourage them to try it. Rather, education can make women with disabilities more comfortable and informed on the subject.

### Risk

Women with disabilities are at a **greater risk for sexual violence**, because they often have to depend on others and have learned to place total trust in others.

### Consent

**All women with disabilities have the right to say “yes” or “no”.** Women with disabilities have learned to be compliant with the wishes of others. They are accustomed to taking direction from others and obeying others. They need to know it is okay to say no if they are uncomfortable, nervous or scared.

### Privacy

Women with disabilities may have **few opportunities for sexual expression** due to a lack of privacy. They need support to explore how to request and access private space for sexual expression, alone or with a partner.

### Diversity

Women with disabilities represent the **same diversity of sexual identity and orientation** as the general population. Some women with disabilities may wish to choose female dating partners or have questions about sexual orientation and identity they would like to explore.

### The Next Step

Think about how you can support your loved one in learning about healthy sexuality and sexual violence. Ask disability service agencies and rape crisis centers to present the education programs that inform and empower women with disabilities. Talk with other parents and guardians to ask for support and quality sexuality and sexual violence prevention education programs for women with disabilities.

If an agency asks your permission to educate your loved one about these issues, learn about the program and find ways to support the program and your family member’s learning experience.





## THE FUNDAMENTALS

The next few pages are quick reference materials regarding women with disabilities, sexuality and sexual violence.

### Myths and Facts

Page 10 is a brief review of common myths and facts about people with disabilities and sexual assault. It is useful to ground yourself about the issue and to share with other family members regarding the reality of sexuality and sexual violence in the lives of women with disabilities.

### Rights and Responsibilities for Women with Disabilities

Pages 11-12 list rights and responsibilities that women with disabilities have. Women with disabilities and their advocates (including parents and guardians) have named these rights as key to their freedom, safety and well being. Think of them as human rights – things all people desire and deserve in their lives.

## MYTHS AND FACTS ABOUT PEOPLE WITH DISABILITIES AND SEXUAL ASSAULT

**MYTH:** I am a child in an adult's body.

**FACT:** I am an adult in all respects, including sexual desires and feelings.

**MYTH:** I am innocent and should stay that way; I don't need to know about sex.

**FACT:** I have a right and a need to know about healthy sexuality and about sexual abuse/assault.

**MYTH:** If I claim to be sexually abused, I'm making it up or seeking attention.

**FACT:** If I get up the nerve to tell you I've been hurt sexually, you need to believe me.

**MYTH:** If I can't communicate in traditional ways, I can't tell you I've been sexually abused.

**FACT:** I can still disclose sexual harm or trauma. Watch my body, face, and emotions for signs.

**MYTH:** You should not believe me if I disclose. I have a history of lying.

**FACT:** People with a history of lying are at higher risk for sexual violence because nobody believes them. I can lie about things and still be abused.

**MYTH:** If I experience sexual violence, I must have done something to cause it to happen.

**FACT:** Sexual violence is NEVER the survivor's fault.

**MYTH:** Because I have a disability, I can never be a credible witness.

**FACT:** With the right support and accommodations, I can tell what happened in court.

**MYTH:** I'm not reacting to trauma. I'm just acting out or having a behavior problem.

**FACT:** I'm trying to tell you something with my actions! Don't punish me. Listen to me! Help me!

**MYTH:** Because I have a legal guardian, I can't give consent for anything.

**FACT:** I still have the right to speak for myself. Check the laws on it!

**MYTH:** If I experience sexual violence, it's usually with a complete stranger.

**FACT:** If I experience sexual violence, it's usually with a family member or caregiver.



## Rights and Responsibilities for Women with Disabilities

The Illinois Imagines team is working to ensure that all women with disabilities are guaranteed the following rights:

- The **right** to live in a world without sexual violence.
- The **responsibility** to treat others' sexuality with respect and cause no harm.
  
- The **right** to be treated with respect and dignity in an accessible environment.
- The **responsibility** to treat others with respect and dignity and to speak up for needed accommodations.
  
- The **right** to speak for themselves and make the decisions that are right for them.
- The **responsibility** to communicate your preferences and desires and to learn from your own actions.

## OUR RIGHTS, right now

- The **right** to information that will help keep them safe from sexual exploitation and violence.
- The **responsibility** to keep informed, to ask questions, and to report unsafe situations to a trusted person.
  
- The **right** to explore and enjoy their sexuality.
- The **responsibility** to keep sexuality private, to communicate when you need more information or when concerns arise.
  
- The **right** to pursue loving intimate relationships with the partners they choose.
- The **responsibility** to communicate openly and honestly; the responsibility to honor other's choices, even if they differ from yours.
  
- The **right** to talk about their experiences freely, without fear of judgment.
- The **responsibility** to listen to others share their stories without judging them; the responsibility to keep other's stories confidential.
  
- The **right** to be heard, understood, and supported in reporting and healing from sexual violence.
- The **responsibility** to state your needs, to ask for help, and to report when sexual violence occurs to myself or others.
  
- The **right** to identify and define their own sexuality and sexual orientation without judgment or discrimination.
- The **responsibility** to honor who I am and how I want to express myself; responsibility to not judge others for who they are.
  
- The **right** to receive and share information in a way that meets their individual needs.
- The **responsibility** to ask for information in the way I need it and to communicate what works and what doesn't work.

SECTION 2  
**PREPARE YOURSELF:**  
**Supporting Sexuality and  
Sexual Violence  
Prevention Education for  
Your Loved One**

ILLINOIS IMAGINES  
OUR RIGHTS  
**RIGHT NOW!**



# TALKING ABOUT HEALTHY SEXUALITY WITH A LOVED ONE

## GETTING STARTED

The majority of parents and guardians have many concerns about their daughter's or son's safety, especially sexual safety. Parents of children with disabilities may feel especially concerned due to the alarming rates of sexual violence against people with disabilities. One of the factors that contributes to the increased risk faced by individuals with disabilities is the lack of information and education they receive on issues related to healthy relationships, sexuality, sexual violence and body safety.

As a parent, you can help reduce this risk by providing your loved one with opportunities for education so they can be more knowledgeable and safe. Learning about our bodies, relationships and sexuality is a lifelong process which begins at birth. Though parents get nervous thinking about having "The Talk," children are learning daily about what it means to be a woman, man or sexual being. As you approach the issues of healthy sexuality and sexual violence prevention education with your child it is helpful to:

- Gather Resources
- Reflect
- Engage your loved one
- Practice
- Know the Basics

The following pages contain tips that can help you feel more comfortable and confident in your ability to educate and empower your son/daughter.

### GATHER RESOURCES

- Find resources that will provide you with the information you need to talk about healthy sexuality with your son/daughter. Try searching the Internet, public library, etc.
- Ask other people about information they might have on this subject. Schools are a good resource regardless of your child's age.
- Talk to community disability agencies about how to approach talking about the subject and any information they might have.
- Contact a rape crisis center and ask about available education and prevention materials.

### REFLECT

You may need to examine your own comfort level with this material. Make sure that you are comfortable using language related to sexuality and body parts (both correct language and slang terms). You also need to make sure that you know and understand the information. You don't need to be embarrassed or ashamed if you are not clear or are unsure if your information is accurate or complete.

Most of us are not accustomed to speaking openly about body parts, sexual acts, sexual violence and other aspects of a risk reduction program. So take the time and opportunity to educate yourself. It is also helpful to discuss the material with someone else or practice doing the activities prior to using them. You may want to ask someone else to help facilitate your conversations with your loved one.

Many women with disabilities may never have had an opportunity to talk openly about these topics. Therefore, it is critical to create a safe, private, comfortable environment for education sessions.



## ENGAGE YOUR LOVED ONE

- Look for natural opportunities to talk about relationships, sexuality and sexual violence. An engagement announcement or a wedding may be a springboard to a discussion on relationships, consent and commitment. The birth of a baby or a new puppy may provide an opening to talk about reproduction and sexual activity.
- Periodically, set aside quiet moments to have a conversation about relationships and sexuality. An extended period of time may be necessary for your loved one to come around to asking you questions about their bodies, interest in relationships or sex.
- Seize the opportunity. If your son/daughter expresses interest in having a boyfriend or girlfriend, weave into the discussion key education points. The most important thing you can do is to honor your child's feelings and keep the door open for future dialogue about relationships.
- Repeat your key message(s) as often as possible. This is important in getting your son/daughter to understand what you are telling her/him.
- Ask your loved one to tell you what they know about their bodies, relationships and sexuality.
- Start at your son/daughter's level of understanding. Build upon what they already know.
- Avoid vague terms that might be confusing.
- Use the correct terms for all body parts as well as sexual activities. In the event of sexual violence, knowing the proper terminology will aid in the investigation.
- Repeat the same consistent message
- Inform important people in your child's life that you are talking about sexuality with your daughter/son.

### Practice

Take advantage of everyday situations to point out the meaning of consent and practice consent. For example, practice asking to borrow items from another family member. Identify the difference between yes and no.

Give your loved one choices in as many areas of daily life as possible. When your son/daughter has consistent opportunities to make decisions, communicate needs and stand up for his/her rights, they are practicing skills that are foundational for healthy relationships and reducing their risk for experiencing sexual violence.

### Know the Basics

When preparing to talk with others about sexuality and sexual violence, it is useful to check facts and study some basic information. This helps build comfort with discussing the information and ensures accuracy of your information. Whether you are initiating discussion with your loved one with a disability or responding to their questions and concerns, it is helpful to review some basic facts.

### What is Sexuality?

Sexuality is more than sexual intercourse/activity. It has to do with:

- Being male or female and how they are alike and different
- How we view our bodies and our relationships with others
- How we grow and change over the years
- Who we are as girls/women and boys/men
- How we reproduce

## Stages of Sexual Development

As with all people, individuals with disabilities will move at their own pace through the stages of social and sexual development based on level of understanding, opportunities to learn social skills and exposure to sexual education. Their bodies are changing, curiosity is growing and interest in developing intimate relationships is natural in all of us. To support healthy relationships in adulthood, each individual needs to successfully pass through the foundational stages of social and sexual development. These stages include:

**Infancy:** healthy human sexual development is nurtured through touch, rocking, feeding, being held.

**Toddlers:** curious about their bodies and may self-explore through masturbation.

**Early childhood years:** children begin to learn how to interact with each other by watching those people closest to them. Behavior then begins to reflect what has been modeled for them.

**Pre-school and Early School years:** children begin to ask more questions and become interested in body differences. They begin to understand what it means to be male or female and form ideas about gender roles.

**Early School Years:** children favor a social interest in either the same gender or in the opposite gender. Both are normal.

**Puberty:** this usually begins between the ages of 9 and 13. This is when there is change physically, emotionally and sexually. This includes rapid bone growth, increased sexual drive, change in hormonal levels and emotional ups and downs due, in part, to uncertainty about what is happening in their bodies.

**Adolescence:** follows the rapid changes of puberty. This can be marked by conflict with adults as the child strives for more independence. It can also be marked by an increase in masturbation for self-pleasure. This is only a problem if it is practiced in public places, if the person becomes guilty or fearful about the behavior or if it causes physical damage.

## OUR RIGHTS, right now

All people need basic information as they pass through the stages of sexual development. Children experiencing puberty and adolescents need to know about:

- Growth spurts
- Breast growth
- Menstruation
- Body/public hair growth
- Acne
- Perspiration
- Birth control (including emergency contraception and sexually transmitted infections)
- Voice Changes
- Wet Dreams

## How Should Parents Approach Sexuality Education?

- Provide correct information.
- Answer questions honestly and use words your son/daughter (regardless of age) can understand.
- Start conversations. Some individuals may never ask on their own.
- Share your beliefs, concerns, and values. Your son/daughter needs to know where you, the parent stands.
- Help your children make good decisions and know how to stand by those decisions.

## Why are People with Disabilities More at a Risk for Sexual Abuse and Assault?

- They are not given critical information.
- They often need assistance with personal care and hygiene.
- They may find it difficult to report abuse because of communication difficulties.
- They are often taught to comply with authority.
- They may be targeted because of their lower intellectual functioning.
- They may not be believed when they report abuse.

## What Can I Do to Ensure My Child with a Disability is Educated and Safe?

- Give them correct information about sex and teach them correct language for body parts.
- Be certain your son/daughter understands the concept of privacy and their right to this.
- Teach about safe touch versus unsafe touch.
- Teach about personal boundaries and when it is ok to say no.
- Teach them they have a right to non-comply when those boundaries are crossed, even if it is someone in authority doing this.
- Role play situations and practice saying no.
- Ensure your son/daughter understands personal rights and their choices.
- Put this into language your son/daughter can understand given their level of intellectual understanding. Find books, videos, etc. that will help do this if necessary.
- Know the signs of sexual abuse, so if this is happening and your child communicates in a non-traditional manner, you will know something is going on and can address this.

## What are the Barriers to Sex Education for People with Disabilities?

- The primary barrier to sex education is the belief that people with disabilities are not sexual and do not need information on healthy sexuality and sexual violence.
- Some people believe that if you have a disability you shouldn't have a sex life or learn about sex since it may give you ideas.
- People with intellectual disabilities are often not told about sexuality in a way they can understand.
- Parents often don't have the information they need to help their child understand about sex.

---

---

**“I have the right to information, community participation, private sexual expression, boundaries in personal care and relationships, and a full life.”**

*Self-advocate response  
to an Illinois Imagines survey question*

---

---

# SECTION 3 SEXUAL VIOLENCE PREVENTION

ILLINOIS IMAGINES  
OUR RIGHTS  
**RIGHT NOW!**



## SEXUAL VIOLENCE PREVENTION

### Find Prevention Services

Parents and guardians feel tremendous responsibility for the safety of their child, youth or adult family members with a disability. It is helpful to know about prevention programs that are available to help you and your loved one with sexual violence awareness and prevention. Contact your local rape crisis center and/or the disability service provider that works with your loved one with a disability. You can find contact information at [www.illinoisimagines.org](http://www.illinoisimagines.org). Ask if they have the curricula kit entitled “Our Rights, Right Now” and if they are planning to conduct any prevention education programs that you and your child will be able to join.

### Support your Child’s Participation in Prevention Education

#### Teach and Practice at Home

In order for a loved one to learn about boundaries and reduce their risk for sexual violence, it is important that they can practice the skills in their home environment. Below are some of the ways that parents and other family members can help teach these skills.

#### Discuss Feelings

Provide opportunities for the person to identify and express their feelings.  
Teach through imitation - express your feelings using “I statements.”  
Provide opportunities for the person to discuss their disability and any related feelings.

#### Practice Saying “No”

Provide opportunities for the person to make choices on a regular basis.  
Define parameters in which the person can say ‘no’ in the home setting (with the people they trust the most). Saying ‘no’ is a skill which requires practice and permission.



### Show Respect for Personal Dignity and Space

- Knock and ask permission to enter the person's bedroom before entering.
- Do not force anyone in your home to hug or kiss someone.
- Seek permission before assisting with personal care activities such as bathing, toileting, and dressing or undressing.
- Give the person feedback if they are 'too close' to you or others.
- Practice socially-acceptable space between the person, yourself and others.
- Actively teach the person a variety of ways to show affection (i.e., high five, hand shake, smile, compliment, hug, etc.)
- Actively teach privacy of locations, activities, body parts and conversations.

### Identify Safe People

- Talk with the person about safe people in their life.
- Provide reminders about safe people.
- Discuss what kind of things the person may want to share with a safe person.
- Discuss how a safe person can listen and be helpful.
- Discuss what can be told.

### Tap into Personal Power

- Listen to feelings and develop a sense of trust with your loved one.
- Answer questions about private body parts, relationships, sexuality, etc.
- People who understand their disability typically have more personal power.
- People with very little personal power are high risk for sexual violence. Help the person know and use their power.
- Focus on the person's skills, talents and dreams for their life.
- Communicate your belief in the person to learn and have a good life.
- Include the person equally in family activities. Respect the person's choices.

## Common Questions

As you prepare and engage in conversation about sexuality and sexual violence prevention with your child, you may have questions and concerns about various aspects of your child's sexuality, prevention education and responding to sexual violence. You are not alone. The following are common questions posed by parents and guardians of children with disabilities, and responses that may be helpful to you.

**Q:** We are concerned about teaching our daughter sex education. We are not sure she will understand it and really don't think she will ever be interested in sex anyway. Why bother?

**A:** You may be concerned because when you hear the words 'sex education' your mind thinks about sex acts. Actually sex education includes topics such as healthy relationships, understanding our bodies, and other important topics. It is important that we all have access to basic information about our bodies, healthy relationships, healthy sexuality and reducing risk of sexual assault. And, although it may be uncomfortable for you to think about your daughter being sexual, most people with disabilities are sexual in nature. Denying people with disabilities critical information renders them at greater risk of sexual assault. Relax, take your time and understand that your daughter will appreciate the efforts that you make.

**Q:** If my child learns about sex won't they then want to have sex?

**A:** All people have sexual feelings and experience sexual changes across their lifespan regardless of whether a person has been taught about sex or not. Learning about sexuality helps individuals make informed choices about relationships and sex. Education is also a good way to protect your child from becoming sexually assaulted or hurt in other ways. Knowledge is power and even for people with significant disabilities the more they know the more they are protected if someone does something to them.

**Q:** It was hard enough to talk about sex to my kids who have no disability. How do I talk to my daughter about these things who is non verbal and who we really don't know how much she understands?

**A:** I think in this situation a good thing to do is to look for books or videos that might help in this area. There are also disability groups to reach out to that might be able to give you some good resources.

**Q:** I want to make sure that my daughter is safe. Is it best for her to live with me in order to prevent sexual assault?

**A:** As parents, we would like to be able to protect our children from harm; however, there is no guarantee of safety regardless of the living situation. Learning to be independent whether a person is living at home with parents, in a group home or alone is the best approach.

**Q:** My daughter has expressed that she wants to get married. I admit that I am afraid that this is not possible for her, but I want her to be happy. How can I support her getting involved in healthy relationships?

**A:** Ask her what she is looking for in a relationship, i.e. someone to go to the movies with, someone who cares about her or someone she wants to marry. Based upon her answer, look for opportunities to involve her in social opportunities outside of work/program times that would support her relationship goals. Depending upon the situation, you may be able to support her by providing transportation, a place to spend time with her friend/boyfriend or money for them to go places together.

**Q:** I have heard that people with disabilities are vulnerable to sexual assault. Why would anyone want to rape someone with a disability?

**A:** Sex offenders choose people to hurt who they think can't or won't resist, escape or tell. Offenders also count on the fact that if someone tells they will not be believed. Rape and sexual assault is about an offender exerting power and control over another individual. Usually, sexual assault is committed by someone the person and family knows and trusts. All people are at risk for sexual assault. When we think about people with disabilities, we want to focus on their abilities and not their vulnerabilities.

**Q:** We think our loved one is gay. What should we do?

**A:** First it is important that you understand that being gay is not a choice people make, it is something that many people are, including some people with disabilities. It is important that you don't try to change your son/daughter, but that you find a way to provide support. You might want to contact a local group for parents, such as PFLAG (Parents, Families and Friends of Lesbians and Gays). They can provide support and information.

**Q: How can I keep my loved one safe from sexual assault?**

**A:** There is no guaranteed way to keep your loved one safe from sexual assault, but here are some things which reduce his/her risk factors. Keep an open relationship. Provide critical information. Give him/her permission to say 'no' to things in his life. Teach about private activities, locations, body parts, and conversations. Make sure he/she has a way to communicate his/her feelings. Teach different ways to express affection and to greet people. Learn what you can and work with others to make sure your loved one is fully educated and respected.

**Q: My child is basically non-verbal. How would I know if he/she had been sexually assaulted?**

**A:** Some people rely heavily on verbal or use of words to communicate their message, while others may primarily use gestures, sounds, and pictures. How does your loved one communicate other needs or problems to you? He/she may let you know about abuse the same way that he/she lets you know when she/he is unhappy about other things. Additionally, you may notice a change in his response to being around others or other people touching her/him. Does your child suddenly seem withdrawn or afraid of other people?

**Q: My daughter has been following around a neighbor boy and considers him her boyfriend. He is always kind to her, but I know that he does not see my daughter as a girlfriend. I am concerned that she will get her feelings hurt.**

**A:** Start with a discussion on boundaries. Your daughter may not understand that following another person around could make the other person feel uncomfortable or scared and may even be criminal. Misinterpreting kindness for attraction is common among those without a lot of experience in intimate relationships. Discuss the difference between acquaintances, casual friends, close friends, family, etc. For example, ask her about the difference in time she spends with a close friend versus an acquaintance or the feelings she has toward an acquaintance versus a family member or close friend. Using this approach as a lead in to discussing the difference between friendship and intimate relationships may make it easier to understand and less of a personal rejection. It is important to follow up with a discussion on boundaries and respecting another person's space in a relationship. The most important thing you can do in this situation is to honor your daughter's feelings and keep the door open for future dialogue about relationships.



---

SECTION 4  
OUR RIGHTS,  
RIGHT NOW:  
WOMEN WITH  
DISABILITIES AND  
SEXUAL VIOLENCE  
EDUCATION

ILLINOIS IMAGINES  
OUR RIGHTS  
**RIGHT NOW!**



## OUR RIGHTS, RIGHT NOW

Our Rights, Right Now is a sexual violence education curriculum designed for women with disabilities. You can support or request this type of prevention education to start the work of keeping your child safe.

If your loved one with a disability is already included in an Our Rights, Right Now prevention education session, that is good news. If she is not, call your local rape crisis center or disability service program to inquire about a program. To locate a rape crisis center, go to [www.icasa.org](http://www.icasa.org). To locate a disability service agency go to [www.dhs.state.il.us](http://www.dhs.state.il.us) and click “office locator.”

The Our Rights, Right Now: Women with Disabilities and Sexual Violence Education lessons are divided into four segments. Overall, the classes focus on healthy relationships and healthy sexuality. Learning about these concepts is one of the best ways to prevent sexual violence. These lessons enable participants to:

- identify relationships they are comfortable with;
- respond to sexual violence, and;
- report sexual violence.

General tips for supporting concepts included in the Our Rights, Right Now program include:

- **“Tell me about what you learned today in class”**
- **“I’d like to hear about something that was talked about during class that you already knew”**
- **“What did you talk about in class today?”**
- **“What was most important about class today?”**
- **“What questions do you have about what you learned today?”**



Be sure to let your family member know that you want them to learn how to be safe. You might say:

- **“I want you to be safe.”**
- **“I am happy you are taking that class.”**
- **“I want you to know what to do if someone tries to hurt you. I care about you.”**

A summary of the Our Rights, Right Now lessons follow. For each lesson, please note the “tip” for ways you can reinforce the lesson. If you have questions or would like to review the Our Rights, Right Now curriculum kit, please call the rape crisis center or disability service provider.



## Section 1 - Healthy Relationships (5 Lessons)

1. **What are Relationships?** – This lesson defines the range of relationships people have, from strangers to intimate partners. The qualities of healthy relationships are defined.

**Tip:** Ask the person to identify people in their life that are acquaintances, friends, best friends, family members and boyfriend/girlfriend. Discuss the importance of having different types of relationships and degrees of closeness. Invite them to share what they like best about a friend (or any other relationship) and how they like to spend their time with their friend(s).

2. **Thumbs Up/Thumbs Down** – This lesson helps participants define healthy relationships by describing healthy (thumbs up) and unhealthy qualities (thumbs down) of various types of relationships.

**Tip:** Talk about the difference between healthy and unhealthy relationships. Ask them to name 3-5 qualities of a healthy relationship and 3-5 characteristics of an unhealthy relationship. Emphasize their right to be respected and treated as a valuable person in all relationships. Explore further any comments which may indicate that someone they know is not treating them respectfully.

3. **Who Would You Date?** – This lesson reinforces lesson two by asking participants to identify qualities to seek or avoid in a relationship.

**Tip:** Invite them to share what qualities they look for in a person they would like to date. If comfortable, share your own experiences with dating as it relates to qualities to seek or avoid in a relationship. If the person is not interested or comfortable discussing an ideal dating partner, discuss healthy and unhealthy qualities in a friendship.

4. **Dating Relationships** – This lesson helps participants identify the goals and qualities of healthy dating relationships. Participants are encouraged to state what they want in a relationship, what they do not want in a relationship or dating partner and how to stand up for themselves in a relationship.

**Tip:** Healthy relationships are based upon respect. Ask them to talk about what respect looks like in a relationship, i.e. you feel good about yourself, you can express your feelings, you can say “no” to the other person. Create opportunities to provide practice for them to stand up for themselves and praise efforts when you see solid assertiveness skills.

5. **Starting a New Dating Relationship** – This lesson uses scenarios to help participants identify safe ways to be in a relationship (e.g. date in public place, make sure your family meets your friend before you date).

**Tip:** Discuss strategies for safety and customize to fit the individual circumstances. For example, places where the person can meet a date, transportation for dates, household guidelines for checking in (if appropriate). Establishing an open line of communication on the subject of dating will help promote healthy relationships as well as safety (emotional, physical, sexual, etc).

## Section 2 - Healthy Sexuality (4 Lessons)

1. **Knowing Our Bodies** – This lesson teaches participants to identify body parts of men and women and when it is okay for another person to touch their private parts, i.e. doctor visits, assistance with personal hygiene activities.

**Tip:** Invite them to share with you what they are learning during class and provide the opportunity for them to ask you questions they may have not felt comfortable asking in front of other group members. “What questions do you have about a female or male body that you would like to ask?” “Let’s talk about what you learned in class?”

2. **Public and Private Behavior** – This lesson defines public and private behaviors. Participants will explore appropriate activities for public (combing your hair, holding your friend’s hand) and private situations (taking off your clothes, going to the bathroom, touching your private parts).

**Tip:** Reinforce guidelines for public and private behaviors. It is not uncommon for individuals to interpret private behavior as “bad” or “naughty.” Be sure to include the message that there are healthy activities that are meant to be private.

3. **Sexuality: Feelings and Actions** – This lesson is a discussion on identifying feelings and actions involved in healthy sexuality. Participants will discuss questions such as, “How do you know when you are attracted to someone?” or “What do you do when you like someone as a boyfriend or girlfriend?”

**Tip:** Feelings of attraction can be confusing, exciting, frustrating, etc. Discussion of their feelings with loved ones can help them navigate the complicated journey of relationships. This doesn’t have to be done in one “talk.” Keep the lines of communication open by occasionally asking if there is someone they are interested in or inquire about their relationship with someone they have previously stated they liked.

4. **Consent** – This lesson will help participants understand the concept of consent (both adults need to say “yes” for there to be consent) and identify how to know if someone else is giving permission. One scenario discussed during class includes: “I’m walking with a friend and want to hold her hand. How do I know if she wants to?”

**Tip:** Take advantage of everyday situations to point out the need for consent. You can be a role model for consent by asking for permission before entering their room or assisting with personal hygiene.

You can create other opportunities for consent. For example: What would you like to see?” “Do you mind if I change the channel to watch a different show? Reinforce their right to choose and say “no.”

## Section 3 – Sexual Violence Risk Reduction (5 Lessons)

1. **Our Rights Right Now** – This lesson identifies the rights of women with disabilities in relationships.

**Tip:** Ask the person to tell you about the DVD they watched in class. Ask, “What did the women in the DVD say about their rights?” Listen to their response. Say, “You have the right to be safe and to get help if someone sexually abuses you.”

2. **What is Sexual Violence** – This lesson defines all forms of sexual violence. Participants will learn the types of sexual violence, who might commit sexual violence and the components of consent.

**Tip:** Invite the person to share what they learned about sexual violence in class. Listen. Ask: “What are some things you can do if someone threatens, tricks or bribes you to be sexual?” Listen and be supportive.

3. **Boundaries** – This lesson clarifies how to understand and protect personal boundaries. Participants will role play situations and practice what to do if someone tries to cross a boundary.

**Tip:** Create opportunities for the person to say yes or no to choices. Note that this is the same as consent in relationships. Respect boundaries with your family member. Ask permission before hugs and touching. Knock on bedroom doors to establish a ‘norm’ of seeking permission and allowing the person to say “no.”

4. **Consent** – This lesson will teach participants more about consent. This lesson includes the qualities of a healthy relationship. The class will learn safety rules they can follow if they feel sexually abused.

**Tip:** It is important that people can say “no” to the trusted people in their lives so they understand they can say “no” to others.



5. **Red Light, Green Light** – This lesson defines safe and unsafe touch. The class will practice identifying safe and unsafe touch. Participants will practice saying “no” to touch they do not want and to say “no” to secrets of a harmful nature.

**Tip:** Keep an open relationship in which the person feels comfortable talking with you if a problem occurs. Listen when a problem is brought up, even if it seems small. This teaches your family member they can tell you things that are important to them. Let them know you are listening and that you care. Talk with your family member about secrets. Secrets to keep are surprises that make us happy. Secrets to tell are ones that hurt and make us feel bad inside. Let your family member know you will love them no matter what they tell you.

## Section 4 – Safety and Support: How to Get Help (5 Lessons)

1. **Ways to Reduce Risk** – This lesson explains risk and how to reduce the risk of abuse. Participants will learn things they can do to stay safe and protect themselves.

**Tip:** Discuss what risk means. Use practical, daily examples of things that could be risky and how to stay safe.

2. **Safe People and Safe Places** – This lesson identifies the qualities of safe people and places. Participants will identify people and places in their lives that make them feel safe.

**Tip:** Encourage a wide range of strategies for keeping safe, such as going out in groups, carrying a whistle, learning self-defense, walking with a pet.

3. **Design a Support Person** – This lesson will identify qualities of supportive people. Participants will learn the importance of having people in their lives they can share their feelings with and go to for support. This lesson will emphasize talking with someone they trust when they are nervous or afraid or if something unsafe, scary or harmful has happened to them.

**Tip:** Ask the person to tell you about the support person they created. Reinforce that this person would be very helpful to them in staying safe or reporting a problem.

4. **Safety Planning** – This lesson will define safety and safety planning through group discussion and role play. Participants will learn how to handle common situations such as, answering the door when they are home alone, responding to invitations to go places with people they do not know, etc.

**Tip:** Help the person create their own personal safety plan. Use pictures, words, newspaper/magazine clips, etc. to communicate safe places & people and what to do in case of an emergency.

5. **Empowerment Graffiti** – This lesson will empower women with disabilities to speak up for themselves and others. Participants will create a personal safety slogan, design a support person, and create a safety plan.

**Tip:** Reinforce the importance of trusting their own feelings. This is an essential safety skill. If a situation or person doesn't seem safe, teach them to listen to their gut feeling and find a way to remove themselves from the situation or seek support from a trusted person.



---

# SECTION 5 RESPONDING TO SEXUAL VIOLENCE

ILLINOIS IMAGINES  
OUR RIGHTS  
**RIGHT NOW!**



## RESPONDING TO SEXUAL VIOLENCE

### Indicators of Sexual Violence

Sexual assault is the worst fear of many parents. We don't want to even think that our child could be the victim of a sex crime. However, we know that persons with disabilities experience sexual violence at alarming rates. 97% of the time, this violence is committed by someone who is known and trusted by the person and the family.

We hope that you and your loved ones are always free from sexual violence. However, we know that people with disabilities experience sexual assault at alarming rates and often experience sexual violence over a long period of time. We want you to be aware of indicators of sexual violence and prepared if your loved one with a disability discloses a sexual assault. You may be the one who gives them the gift of safety and healing.

It is important for you, as a parent or guardian to be aware of key indicators of sexual violence. You are in the ideal position to note physical, emotional or behavioral indicators of abuse.

It is an extremely difficult thing to talk about, and some people with disabilities do not communicate in a way that is easy for us to understand.

It is important to be aware of any changes in behavior, mood, personality, and/or physical condition. How can a parent know when their loved one may have been sexually assaulted?

The following are some specific signs of possible sexual assault:

- Torn clothing
- Difficulty walking
- Stained clothing/bed/bedding
- Vaginal bleeding
- Pain going to the bathroom
- Bruising in the genital area
- Bruising of the inner thighs
- Sexual talk or behavior
- Vaginal infections
- Unexplained gagging
- Sexually transmitted infections
- Urinary tract infections
- Sleeping disturbances (nightmares, insomnia, excessive sleeping)
- Unexplained abdominal pain
- Depression, anxiety
- Physical or sexual aggression
- Physical evidence of pornography or prostitution
- Itching or swelling in the genital area
- Clothing on backwards
- Difficulty sitting
- Rectal bleeding
- Pain in the genital area
- Incontinence
- Pregnancy
- Extreme changes in behavior
- Changes in eating habits
- Fear reactions to person, place, objects, etc.
- Self-destructive behavior
- Extreme reaction to bathing or other physical care giving
- Inserting objects in vagina or rectum

Please note that any extreme change in behavior can be the result of physical pain the person is experiencing, so health concerns need to be checked out by a physician. Many of these indicators can result from other life events and traumas beside sexual assault. The best way to approach your son or daughter if you observe these possible signs is to be open and caring. The biggest concern that victims of sexual violence have about telling is that they will not be believed. So be prepared to believe whatever your loved one says. People rarely lie about being sexually assaulted.

If you observe a change in your loved one, you might show your concern by saying, “I have noticed that (describe change). I wonder what has happened.” Then be quiet and allow them to think and talk. The question to ask is “What has happened to you?” rather than “What is wrong with you?” When someone experiences sexual violence, it is also traumatic for their loved ones. Both you and your loved one can get help. You may call your community rape crisis center anytime of the day or night. The crisis worker can give you information and support. The rape crisis center services are free and confidential. A listing of Illinois rape crisis centers can be found at [www.icasa.org](http://www.icasa.org).



### DISCLOSURES

As a parent or guardian, you are a primary resource of support and aid for your loved one with a disability. It may be that you are the first person she chooses to talk to if she experiences sexual violence.

Here are things for you to remember if your loved one tells you they have been a victim of sexual assault:

#### Immediate response

##### **Tune in/Listen:**

- Take a deep breath.
- Be quiet and let them tell the story.
- Keep breathing.
- Stay as calm as possible.
- Believe what they tell you.
- Do not blame or judge or punish.

##### **Say:**

- I believe you.
- I am sorry this happened to you.
- This was not your fault.
- You are not alone.
- You are brave to tell.
- Thank you for trusting me with this.

**Ask:** How can I help you? What do you need right now?

**Tell:** A crisis center in town can help you – on the phone or in person.

**Help:** Would you like to call them? I can help with that if you want.

**Protect:** What would make you feel safe right now? Let's make a safety plan.

## Considerations

The rape crisis worker can help you and your loved one decide whether to go to the Executive Director and report the abuse to law enforcement. The center has workers on call 24-hours per day to provide information and support as well as in person accompaniment to hospitals.

If your loved one does not wish to call, or have you call the rape crisis center, you may wish to call the rape crisis center at another time to get information and support for yourself.

## Ongoing Support

**Do not push** your loved one to talk about the experience.

**Restore** your loved one's sense of control. Allow her to help decide what to do. Provide assurance that you will be there to help.

**Be honest** with your loved one. Share what you know. Trust is more important than ever at this time.

**Give** your loved one safety information, but avoid causing more fear of people.

**Maintain routines** and return to your family's usual activities as soon as possible. Don't become too protective. You want to calm any sense of emergency and not escalate the fear and anxiety.

### SELF-CARE

It may be your biggest fear: finding out that your child has been hurt. As parents we want to protect our loved ones from all harm, but that isn't always possible. When something bad does occur, you may turn your focus toward helping them and meeting their needs. The problem is that you may forget to take care of yourself. Rape can traumatize not only the victim, but also family and friends, so it is essential to pay attention to how the sexual violence against your child has affected you.

#### **Some tips to help a parent heal and take care of yourself:**

**Remember:** Sexual violence is never the victim's fault. Likewise, it is not your fault. The fault for sexual violence lies only the perpetrator.

**Accept your feelings.** It's okay to feel angry, hurt, fearful, guilty or numb. Those are natural responses to the situation. Keep a journal and write down your feelings. This may help you verbalize what you are thinking and feeling.

**This is not the time to for you to be "tough."** It can be helpful to say out loud the thoughts you have been keeping bottled up inside. Seek out a trusted friend, counselor, or spiritual leader for support. Talk with someone other than the victim about your feelings.

**It is natural for a parent to want to seek revenge against the abuser.** This will cause more problems and divert you from the main goal: helping your son/daughter and your family recover.

**Take care of yourself and remember your son/daughter needs you more than ever.** You may feel angry or upset that your child did not tell you sooner or embarrassed that this happened to someone in your family. These are normal feelings you may wish to share with a rape crisis center counselor.

**Be patient with yourself.** Many parents experience a feeling of loss or grief, sensing a change in their family dynamics. Healing takes time. Recovery from sexual assault is a process and can take victims as well as family members a long time.

**Take advantage of free, confidential services for family members that are offered through the local rape crisis center.**

---

# SECTION 6 RESOURCES FOR PARENTS AND GUARDIANS

ILLINOIS IMAGINES  
OUR RIGHTS  
**RIGHT NOW!**





# EDUCATION RESOURCES FOR PARENTS AND GUARDIANS

There are many resources available to assist in educating parents who have family members with disabilities about issues of sex and sexuality. In addition to browsing libraries and searching the Internet for resources, some specifically helpful resources are identified on the following pages.

- Links ..... Pages 44-45
- Books ..... Pages 45-47
- Articles ..... Page 48
- Videos ..... Page 49
- Sexual Abuse Resources..... Page 50

### LINKS

#### **Autism Speaks**

[www.autismspeaks.org](http://www.autismspeaks.org)

This website includes information on puberty and sexuality education for parents who have sons/daughters on the Autism Spectrum.

#### **Diverse City Press, Inc.**

<http://www.diverse-city.com/display.htm>

A small publishing company which aims to provide educational materials for people with disabilities and their care providers. The company is informed by the disability rights movement, and is closely linked with organizations and individuals fighting for the rights of all people with disabilities to take control of their own lives and control their own fate.

#### **National Down Syndrome Society**

The National Down Syndrome Society provides an information packet and list of books regarding several issues facing people with Down Syndrome including sexuality issues.

666 Broadway, 8th Floor

New York, NY 10012-2317

1-800-221-4602

Web Site: <http://ndss.org>

#### **PACER Center**

This Minnesota-based parent-to-parent organization has published numerous items of interest to families of children with disabilities.

8161 Normandale Blvd.

Bloomington, MN 55437

Minnesota: 1.800.537.2237 or 952.838.9000

TTY: 952.838.0190

USA: 888.248.0822

Fax: 952.838.0199

Web Site: [www.pacer.org](http://www.pacer.org)

#### **Planned Parenthood Federation of America**

Planned Parenthood Federation of America serves as a clearinghouse and library of more than 20,000 items including curricula, pamphlets, books for professionals, and Resource Guides.

1110 Vermont Ave. NW, Suite 300  
 Washington, DC 20005  
 202-973-4800  
 FAX: 202-296-3242  
 Web Site: <http://www.plannedparenthood.org/>

### SexEd Library

SexEdLibrary is a comprehensive online sexuality education resource, with up-to-date, relevant content and the tools with which it is taught. Lesson plans, information and statistics, and professional development courses can be accessed on their site.

SIECUS DC Office

1706 R Street, NW

Washington, DC 20009

Phone: 202/265-2405

Fax: 202/462-2340

Website: <http://www.sexedlibrary.org/>

### The National Information Center for Children and Youth with Disabilities

<http://www.nichcy.org/resources/sexualityeducation.asp>

The National Information Center for Children and Youth with Disabilities still remains relevant despite its age. Sections include information on defining sexuality and how it develops, social skills, teaching children about sexuality, affects of disability on sexuality, and relationship issues for young adults.

## Books

Anderson, O. H. (2003). *Doing what comes naturally: Dispelling myths and fallacies about sexuality and people with developmental disabilities*. Decatur, IL: Blue Tower Training Group.

**Description:** This book first challenges the beliefs and attitudes of family members, educators, and DD professionals concerning the sexuality of people with developmental disabilities. It then guides them in meeting the social-sexual needs of the people they love and serve. Overflowing with passion and filled with wisdom, this book provides a philosophical, yet practical, definition of sexuality.

N. Baladerian, Ph.D. and J. Nunez. *The Rules of Sex: For Those Who Have Never Been Told*.

**Description:** This book, available in print or as a PDF, is written with and for individuals who have never had a concrete description of “the rules of sex,” and may get or may already have gotten in trouble just for lack of information. Written for young adults. Available in English and Spanish from the Disability, Abuse, and Personal Rights Project of Spectrum Institute at <http://www.norabaladerian.com/books.htm>

Couwenhoven, T. (2007). *Teaching children with down syndrome about their bodies, boundaries, and sexuality: A guide for parents and professionals*. Bethesda, MD: Woodbine House.

**Description:** A comprehensive “how to teach sexuality” resource that offers practical information on teaching ideas for addressing a wide variety of sexuality issues across the life span. Includes “use at home” activities that are useful for teaching about the body, privacy, relationships, and exploitation prevention. Detailed and realistic drawings that can be used for teaching are included in the appendices.

Couwenhoven, T. (1991). *Beginnings: A parent/child sexuality program for families with puberty-aged children with developmental disabilities*. Wisconsin Council on Developmental Disabilities.

**Description:** Ideal for professionals setting up parent/child puberty workshops.

Drury, J., Hutchison, L. & Wright, J. (2000). *Holding on, letting go: sex, sexuality, and people with learning disabilities*. Souvenir Press.

**Description:** Discusses general information about sexuality from the perspective of parents and professionals as well as strategies for working together on issues.

Future Horizons (2003). *Taking care of myself: A hygiene, puberty, and personal curriculum for young people with autism*.

**Description:** This book is essentially a social stories curriculum for teaching about body changes, appropriate sexual behavior, and encouraging independence with hygiene and self-care. It also includes ideas for teaching tools using Boardmaker© and Picture This© symbol programs.

Hingsburger, D. (2001). *I Contact: Sexuality and People with Developmental Disabilities*. Mountville: Vida Publishing.

**Description:** Parents ask questions about sexuality and children with developmental disabilities.

McKee, L. & Kempton, W. (1987). *An easy guide to loving carefully for men and women*. Sacramento, CA: ETR Associates.

**Description:** A well-illustrated book which explains birth control and sexual health in very simple language. Requires reading skills.

Schwier, D. M. and David Hingsburger (2000). *Sexuality: Your sons & daughters with intellectual disabilities*. Towson, Maryland: Brookes Publishing Company.

**Description:** This book is designed for parents, helping them to make sure their child develops healthy sexuality, that sense of self and confidence that helps make us all well-adjusted and strong individuals. It focuses on interacting with your children - no matter their age or ability - in a way that increases self-esteem, encourages appropriate behavior, empowers them to recognize and respond to abuse, and enables them to develop life long relationships. Both parents of people with intellectual disabilities and people with intellectual disabilities themselves are referenced.

Schweir, D. M. (1994). *Couples with intellectual disabilities talk about living and loving*. Rockville, MD: Woodbine House.

**Description:** This book provides information to parents and caregivers on interacting with their children (regardless of age or ability), in a way that increases their self esteem, encourages appropriate behavior, empowers them to recognize and respond to abuse, and enables them to develop lifelong relationships. Throughout the book, parents share the joys and challenges of raising a child with an intellectual disability as they offer advice and practical strategies, while individuals with disabilities share information about what is important to them.

Siegel, P. (1991). *Changes in you*. Richmond, VA: Family Life Education Associates.

**Description:** A clearly illustrated, simply worded explanation of the changes of puberty for girls and boys. Includes a Parents' Guide.

### ARTICLES

Maksym, D. (1990). *Shared feelings: A parent guide to sexuality education for children, adolescents, and adults who have a mental handicap*. North York, Ontario, Canada: G. Allan Roeher Institute.

Pacer Center, Inc. (1996). *I am a beautiful person: Sexuality and me*.

**Description:** 13:35 minute video for parents of teens with disabilities. This video demonstrates how all people can live their lives as healthy sexual beings. Designed for viewing by parents and caregivers, it includes interviews with people of varying ages and abilities.

Impact - Feature Issue on Sexuality and People with Intellectual, Developmental and Other Disabilities. Published by the [Institute on Community Integration \(UCEDD\)](#) and the [Research and Training Center on Community Living](#), College of Education and Human Development, University of Minnesota • Volume 23 • Number 2 • Spring/Summer 2010

## VIDEOS

### ***Doin' It: Sex, Disability and Videotape.***

The Empowered Fe Fes, a peer group of young women aged 16-24 with different disabilities, produced this award-winning video investigating sex and disability. In it they think about the topic from many perspectives by talking with activists and scholars. The viewer tags along on a date between a woman with a disability and her able-bodied boyfriend as they explore issues in dating with a disability over a candle-lit dinner. Available from Beyondmedia Education in Chicago at <http://beyondmedia.org> or 773/857-7300.

### **Person To Person** (1991), [www.johncarmody.net/clients/choices/](http://www.johncarmody.net/clients/choices/)

*Person to Person* is a ground-breaking video that set the standard for sexuality education of persons with cognitive challenges. It shows the techniques of expert educators as they provide information on topics such as menstrual hygiene, sexually-transmitted diseases, personal space and safety issues, appropriate behaviors on the job and in public places, and marriage for people with special needs. This video will demonstrate to you that sex education can make a difference!

### **No! How!!!**, [www.diverse-city.com](http://www.diverse-city.com)

For too long others have determined what people with disabilities need to know to stop victimization. This video involved people with disabilities in acting, writing, producing and directing a film aimed at others with disabilities. From discussing disability to teaching boundaries and body parts, people with disabilities take the lead.

### Special Purpose Films. *Learning to talk sex when you'd rather not.*

**Description:** Excellent for training about people with developmental disabilities, their parents and care providers. Shows un-staged scenes of men and women learning safety, appropriate private and public behavior, and human anatomy. 30 minutes.

## SEXUAL ABUSE RESOURCES

Baladerian, N. J. (1993). *Abuse of children and adults with disabilities: A prevention and intervention guidebook for parents and other advocates*. Culver City, CA: Disability, Abuse and Personal Rights Project.

**Description:** This publication discusses increased vulnerability to abuse, the signs and symptoms of abuse, consequences of abuse, the abusers, how to report suspected abuse, intervention and examples of risk reduction strategies.

Bissada, A, Scher, L., Wiper, A. M., & Oya, M. (2000). *Keeping our children safe*. California State Council on Developmental Disabilities program Development Fund, Cycle XXII.

**Description:** A booklet for caregivers and providers of children with developmental disabilities to reduce the risk of abuse.

Hingsburger, D. (1995). *Just say know: Understanding and reducing the risk of sexual victimization*. Newmarket, Ontario: Diverse City Press Inc.

**Description:** This book explores the victimization of people with disabilities and helps reduce the risk of sexual assault. The ring of safety presents the skills to teach people with disabilities to enable them to protect themselves. The book also presents a new way of looking at the indicators of sexual abuse in the population of people who have developmental disabilities.

Paceley, S. (2003). *My body... my choice*. Decatur, IL: Blue Tower Training Group.

**Description:** This fully illustrated mini-book is written for adolescents and adults with developmental disabilities. **My Body...My Choice** covers the basics of body safety and is empowering people with disabilities across the nation to resist and report sexual abuse.

Schaefer, Karen. (1993). *What only a mother can tell you about child sexual abuse*. Washington, DC: Child Welfare League of America, Inc.

**Description:** A valuable resource for parents of child victims of sexual abuse and for professionals who work with victims and their families.