



By

Linda Sandman, Katie Arnold, Lex  
Bolyanatz, Carli Friedman, Cathy  
Saunders, & Tara Wickey

# Acknowledgements



This booklet was produced with the support of a grant from the UIC Institute for Policy and Civic Engagement.

The Sexuality and Disability Consortium wants to recognize our community partners who helped plan and host the **Community Research Forum: People with Intellectual/Developmental Disabilities Advancing Sexual Self-Advocacy**.

- Cathy Saunders, **Illinois Imagines**
- Tara Wickey, **Illinois Self-Advocacy Alliance**

We also want to thank the many self advocates who participated in the forum and shared their knowledge with us.

# Introduction



On March 21, 2014 at the Institute  
on  
Disability and Human Development  
at UIC

**30 people with intellectual and  
developmental disabilities  
gathered to talk about what  
sexual self-advocacy means to  
them.**

# **SEXUAL RIGHTS OF PEOPLE WITH DISABILITIES**

All people with disabilities have the same rights to sexual expression as all other persons in society.

These rights include, but are not limited to:

- 1. People should not judge you for being yourself or for who you are with.**
- 2. You have the right to ask someone questions and to learn about sex and safety and your health.**
- 3. You can speak up about relationships and choose for yourself who you want to be with.**
- 4. People have to respect your privacy and respect your rights and treat you nicely.**
- 5. You have the right to be safe and no one should abuse you or hurt you or judge you. Stand up for yourself!**

## What is Sexual Self-Advocacy?



**My Choices** means that people can make their own choices about what they want and how they express their sexuality. The choices you make are your own and reflect your life experiences and values.

“Being confident in choosing my boyfriend.”

“Choosing to have sex.”

“Not have sex until you’re married.”

“I like to be happy and intimate and truthful & I have the right to say no.”

“Talking about sex. Feeling comfortable with one person.”

## What is Sexual Self-Advocacy?



### **Knowing & Respecting Myself**

means being comfortable with yourself and respecting yourself. Every day you can learn about yourself—about what you want, what you need, what is important to you and what you wish for in a healthy relationship, including how to love yourself.

**“Respect, dignity for oneself.”**

**“My view of self-advocacy is powerful, independence, strong and love.”**

**“My morals, my voice, love and respect.”**

**“Be comfortable with yourself.”**

## What is Sexual Self-Advocacy?



**Respect for Others** means respecting other people in the way they communicate about their sexuality and the choices they make. It is also about respecting what the other person in the relationship likes and wants.

**“Respect other people.”**

**“Respecting other people’s wishes in a relationship.”**

**“I be happy about being loyal and responsible.”**

**“Friends, trusting friends—your responsibility.”**

## What is Sexual Self-Advocacy?



**Respect My Rights** means that rights are something that each person has and under which all people are protected. Self-advocates know that they have rights and that other people should respect their rights and boundaries.

“Standing up for your rights and telling someone your rights.”

“Don’t judge or discredit my opinions.”

“I have the right to do stuff like have friends over.”

“Don’t discredit my decision-making.”

“Try to stand firm and be strong in your convictions.”

## What is Sexual Self-Advocacy?



**Speaking Up** means that you can use your voice to speak up for yourself and others. Everyone's voice is important and deserves to be heard and respected. Speaking up for others shows support for other people with disabilities. You can speak up for yourself or others in all kinds of relationships, including with friends, partners, family, staff and law enforcement.

**“Telling someone what you want and what you don't want.”**

**“Not feeling like a victim when you are saying something important.”**

**“The freedom to speak your mind.”**

**“Speak up for those who need help talking about sexual self-advocacy.”**

## What is Sexual Self-Advocacy?



**Getting Information** means learning about relationships and safety. It is important to learn how to find the information and who to ask for the information. It is important that you can understand the information and that it makes sense to you and your life.

“How to ask someone out.”

“Asking if having sex will be a one night stand or long term.”

“Skill. Parts of the body. My choice.”

“Family—they help you speak out against abuse & train you about safety.”

“If two guys want to get it. If two girls want to get it.”

## What is Sexual Self-Advocacy?



**Healthy Relationships** means self-advocates believe communication is important in a relationship. This also includes a feeling of respect between both partners. When a relationship is healthy, self-advocates feel comfortable, loved, happy and successful. Both partners accept responsibility and express their sexuality in safe and healthy ways.

**“We’ve got sex. Success. Power. Fun. Respect. Beauty. And the other word is love.”**

**“Be happy with each other.”**

**“Saying what I will or will not consent to in an intimate relationship while attending to the needs of my partner.”**

**“My boyfriend is nice. Be nice. Special”**

## What is Sexual Self-Advocacy?



### **Interdependence is part of all the themes of Sexual Self-Advocacy:**

Sexual self-advocacy, just like in the whole self-advocacy movement, does not function all by itself. Instead, self-advocates work to support each other as they practice sexual self-advocacy. And other people in their lives also can provide support and assistance for sexual self-advocacy. For example, they can help adults with I/DD build skills for developing romantic relationships and for sexual expression. The six themes that self-advocates use to describe sexual self-advocacy share a common thread that is centered on social and inter-dependent relationships.

## What is Sexual Self-Advocacy?

**Interdependence means:**

**“I need friends. I need help.”**

**“Speak out and get support.”**

**“Meet other people. Got to have friends.”**





We asked self-advocates to vote on which theme was the most important part of what sexual self-advocacy meant to them.

**And the winners were:**



**1. My choices**

**2. Speaking up**

**3. Respect my rights**



We also asked  
self-advocates:

**What needs to  
change?**

## What needs to change?



**Educating Others**—Self-advocates believe educating other people such as doctors, staff, and guardians, is important so they can provide respectful support. This includes training others about disability and how to respond to questions about sexuality in a way people can understand.

**“You can tell your staff not to go into the doctor’s office with you. You have a choice.”**

**“Have classes for professionals and teach their staff that don’t shy around from it. People like us need to have relationships too.”**

**“Training people like my doctor, on how to talk to people with disabilities.”**

## What needs to change?



**Removing Systemic Barriers** – Self-advocates believe that there are many barriers that people need to recognize and take down so that people with disabilities can be sexual self-advocates. Attitudes need to change so that others will accept self-advocates’ sexual rights and guardians will support self-advocates’ choices. Care providers need to respect the privacy of people with disabilities.

**“A lot of times free clinics are not accessible for people with disabilities.”**

**“Professionals sometimes scared to talk about it because they don’t know what’s appropriate & what’s not.”**

**“I go to the doctor and he has a hard time looking at me.”**

## What needs to change?



**Expanding Access to Information & Sexual Health Services**—Self-advocates want increased information about sex, including safe sex practices, different types of relationships and different sexual desires. Self-advocates state that it is important to have access to sex education classes and accessible health services. They want to be able to ask partners, family, doctors and staff about sex.

**“More sex education classes.”**

**“It would help if you had diagrams. You know, like the male part and the female part.”**

**“If you are going to have sex, it is important to take a health class.”**

**“What to do with females. Safe sex.”**

## What needs to change?



**Increase Access to Counseling as a Supportive Service** – Self-advocates want people with disabilities to have more access to counseling so they can talk about their feelings about sexuality and relationships. Counseling is a supportive relationship that has the goal of promoting sexual self-advocacy whenever possible within a safe space.

**“Counseling information about how to inform people about sex.”**

**“Informational talking about how you’re feeling.”**

**“Having staff open to discussing it with you.”**

## What needs to change?



**Developing Opportunities for Sexual Expression**-Self-advocates believe people with disabilities need opportunities to express their sexuality in the way they choose, including private space and private time. They also need more opportunities to meet people and practice and build skills for dating and relationships.

**“Have condoms for women.”**

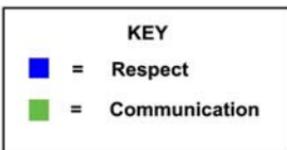
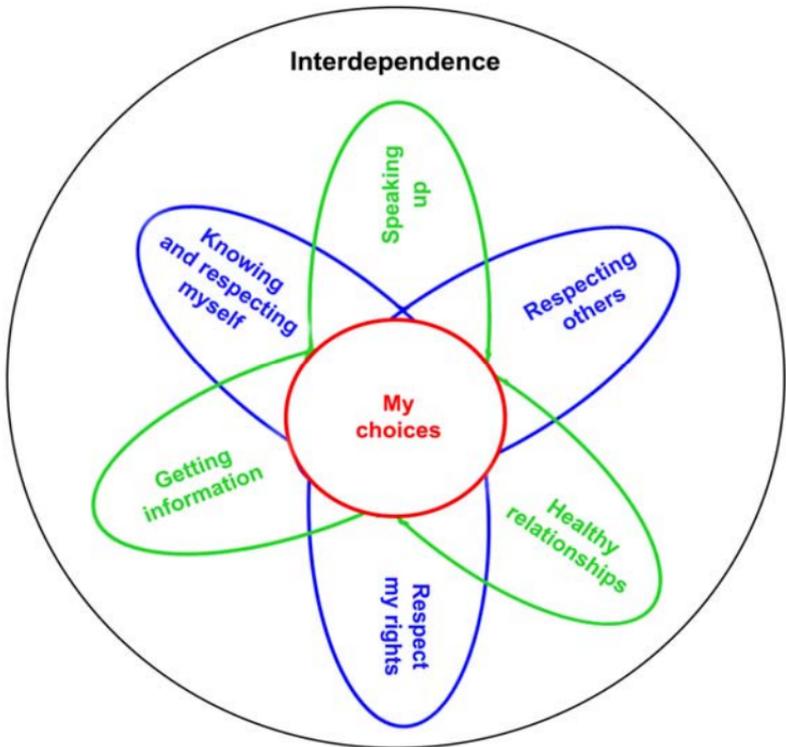
**“People like us need to have relationships too.”**

**Some people may not know what they want . . . go get to know the person.”**

**“Some people wear condoms to protect against HIV & STD. That is very important.”**

## Sexual Self-Advocacy

Everything self-advocates said about sexual self-advocacy is connected, as shown in this picture. Each theme also reflects the interdependence self-advocates experience as a core value.





We invite you to watch the  
video produced at the  
Community Forum at this link:

**“In my voice”**

<http://ahs.uic.edu/dhd/sdc/resources/>