

SELF-ADVOCATES SPEAK UP

ABOUT SEX

Compiled by Karen Topper and Katherine McLaughlin

Members of Green Mountain Self-Advocates in Vermont held a discussion group about sexuality for the purpose of sharing their thoughts and experiences. Here are their candid responses to a number of questions about the messages they received about sexuality over the years, and why they think sexuality education is important.

This is a record of the conversation as it occurred. In some places they respond to one another, as well as to the questions. Their real names have not been used at their request.

Who first explained sex to you?

Roy: My parents, then my friends in much, much more detailed discussion.

Amber: I learned about sex in a sex education class by watching a movie in school, in 4th or 5th grade actually. I was mainstreamed.

Rebecca: I have no idea. In school, it was like child development class or I want to say maybe in 6th grade we watched a movie. I don't know if it was about sex, but I think it was about reproduction.

Julie: My Mom did talk to me. It was hard for her. It was kind of awkward for me.

Molly: My grandma talked to me about sex. I don't know why. It was awkward though.

Elizabeth: I got the talk from my brother. It was awkward, embarrassing, but it was helpful.

Justin: I got the talk from my cousin. He said this is what it is, now go do it.

Gabrielle: Seriously, I've never gotten the talk.

Molly: I've seen having sex on TV.

Justin: Go on the Internet and you can find it. You watch any channel on TV and you can see it. It is on soaps.

What were the messages you got about sex from adults when you were growing up?

Jennifer: Don't have sex. And I agree with them. Don't have sex. You will get pregnant and die. My parents would say, "Ou, ou, gross, sex."

Andrew: You're not ready to have sex.

Gabrielle: Make sure you are protected before having sex.

Andrew: You can't handle having sex.

Molly: My favorite one is, don't have sex until you get married.

Justin: You are not financially stable.

Clara: Like if a guy has a disease in his body, you have to be careful of that.

Amber: From the sexuality class I took last year, I learned to come right out and say it – "get tested" – because you don't know what is out there.

Ida: You can get AIDS and HIV. When I was in 6th grade we did a unit on AIDS and HIV. The best way to avoid that is abstinence, not to have sexual intercourse. They did it on HIV and Ryan White and hemophilia.

Rebecca: Actually I was told if I kissed somebody I would get pregnant.

Did you get any positive messages?

Roy: That is was okay and natural.

Kevin: My parents were always telling me it is a great, great thing, but be careful with it.

Andrew: That it is fun.

Elizabeth: My aunt told me it was refreshing.

Henry: If you have sex, do it behind closed doors. Make sure they lock and nobody can come in.

Ida: Puberty is part of becoming an adult.

Rebecca: Yes, no one explained puberty to me. I had to learn it by myself.

Ida: Especially for some of us for whom it was a surprise and we got it early. My period came early and I said what is this crap?

Rebecca: Mine happened in a movie theater. I went in the bathroom and I said what is this mess?

Clara: When I was young I read this book about becoming a woman. It talked about your feelings and your body.

Adam: Looking back on the messages I got... Wrap your dick.

Jennifer: I don't get it? (Someone explained it meant putting a condom on your penis).

Adam: One that I got that was really helpful was sex is more than just intercourse.

Andrew: It is not all about sex.

Did you get any positive messages, like you look really attractive, hot, you're sexy?

Adam: Not as much in high school.

Henry: Not really.

Molly: This guy tried to pick me up and said I was good looking. And I don't think I am good looking.

How did you feel about the messages you got?

Molly: It felt like I was kid. I am 23 years old and I can do whatever the hell I want.

Did you ever notice if the messages you got were different than the messages given to your sisters or brothers?

(A resounding yes! Even from people who had been quiet up until this time.)

Justin: Just because I have a disability it doesn't mean I can't have a normal relationship.

Molly: I know my sister and brother got the talk. They don't treat me like a normal human being.

Amber: That is because you have a disability and they think you are not.

Elizabeth: I can tell you, nobody is normal in this world.

Andrew: What is normal?

Justin: It is a dial on your washing machine.

Andrew: Normal is just being yourself.

When people talk to your brothers and sisters and not you, what message does that give?

Gabrielle: They wanted me to learn it on my own.

Ida: They want to shelter you, protect you.

Jennifer: All they say is, "Ou, don't do it." Thanks for helping me.

Justin: They want to save you and shelter you. They want to be the momma and poppa bear.

What was the most important thing you learned about sex from adults when you were growing up?

Elizabeth: Wait until you are married for the first time.

Gabrielle: If you want it, use protection.

Clara: Find a good guy. Choose the right one and don't do it spur of the moment.

Adam: Sex is more than intercourse.

Andrew: Make sure you are ready for it, ready for the responsibility.

What do you wish adults would've told you but didn't?

Gabrielle: If I had known everything that I know now, I probably would have waited.

Ida: I wish they had given me an introduction to puberty.

Adam: The only thing I can think of that I would have wanted to learn at an earlier age is what a vasectomy is. I don't have other regrets because people did talk to me about 90% of it. I got my information from a special ed class. But other kids were jealous of me because of the information I got. It was better than the regular classes, which were just about diseases, that's it.

Roy: The opposite of what they told me. They told me "don't do it," "be careful," and "keep it in your pants." Instead of making it so vague with one-phrase sentences, say "It is okay." Kind of give more of an explanation.

Why do you think people with disabilities need sexuality education?

Roy: So we can learn to have healthy relationships.

Rebecca: So we are able to make informed choices.

Elizabeth: So we can pick the right person.

Adam: For help with the toughest part of the relationship, making it last.

Gabrielle: So we can be safe.

Andrew: Because we all have desires/needs and that's okay.

Clara: To get correct information.

Kevin: To get resources/tools to make healthy sexual choices.

Roy: So that people know their rights.

Molly: So people with disabilities don't put themselves in bad situations.

Julie: So we will know how to protect ourselves.

Karen Topper is the State Coordinator for Green Mountain Self-Advocates, Montpelier, Vermont; she may be reached at topper@sover.net.

Katherine McLaughlin, M.Ed. is a national expert and trains individuals, staff, and parents on sexuality and developmental disabilities. She teaches sexuality education to people with developmental disabilities and trains them to be peer sexuality educators. She is the author of an agency and school curriculum, "Sexuality Education for People with Developmental Disabilities." She has developed two online courses: "Developmental Disability and Sexuality 101" for professionals and "Talking to Your Kids: Developmental Disabilities and Sexuality" for parents. She has spent her career trying to elevate the status of all people, which is why the name of her growing company is Elevatus Training.