What Self-Advocates Want You To Know

June 1, 2020

Dear Service Providers,

As you work through the review, selection and implementation of sex education curriculum to use at your agency/organization, we want you to hear our voices and keep these words with you during the process:

“I want to know more so I can decide what is right for me.”
“My body, my choice.”

Relationships are important to our well-being and survival. No one really talks with us about healthy sexuality or relationships. We want to learn about healthy relationships and sexuality, and that information includes relationship and sexual rights; identity; boundaries; safety; violence prevention; communication; giving and getting consent; names for body parts; the physical and emotional aspects of relationships; and what are healthy relationships vs unhealthy relationships. Advocacy has to be part of these conversations; we need to know how to advocate for what we want and what we don’t want. We want to be part of conversations to change policies and procedures so that we can have more freedom to date, hang out with friends or romantic partners.

“I didn’t receive any information in school or from my provider.
I learned by the ‘school of hard knocks’.
I am still trying to work through the trauma of learning the hard way.”

Many of us didn’t receive any information about healthy relationships and sexuality growing up or as adults. We may have received some information but it wasn’t always in a way we could really understand. We want to learn using educational resources and materials that include music, discussions, books, activities, videos, worksheets, and visuals. We want information that is in plain language and easy to understand. We want resources that are written by people with disabilities for people with disabilities. We want the information presented in a few different ways because not everyone learns the same way.

"We had classes at the group home in the past, but it's been a long while. I can't remember what I learned."

We have lots of ideas on how classes should happen. Depending on the topic, it may be best to have all women in a class or all men in a class instead of being mixed. There may be times it would work to have mixed gender classes - ask us what would be most comfortable for us! Classes can be either once a week, twice a month, or once a month. They shouldn't be longer than an hour and half. Have a table or place/space at the classes where all kinds of brochures and information can be placed for us to check out and take - advocacy, food pantries, sexual assault centers, transportation, mental health, etc. Instructors should be flexible as discussions and disclosures occur. All classes must include time for discussion and for people to share their stories if they want. Include information on where to go to get help because we have scars and the scars take time to heal. Classes should create safe spaces each and every time for people to share, learn, disclose.

"We learn best from people like us."

We want to help teach the classes. We can go through the classes and then help teach the next set of self-advocates. There are also self-advocates in the community that can help teach the classes.

A Message of Thanks from the Illinois Self-Advocacy Alliance, Inc.

Thank you to the many self-advocates who participated in focus groups, sharing experiences and speaking up about healthy relationships and sexuality. Your voices started the process that led to HB3299 being passed, and they continue to inform and guide as providers comply with the rule. We honor your voices, your experiences, and your stories. Continue to speak up and speak out!

Illinois Self-Advocacy Alliance

Illinois Council on Developmental Disabilities

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