



SARTAC

Self Advocacy and Beyond



Starting the Conversation

A toolkit for self-advocates to talk about
sexual violence in their community

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in partnership with Self-Advocates of Indiana

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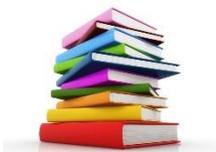
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Introduction

About me:



My name is Kelsey Cowley. I am 30 years old and I live in Avon, Indiana. I am the Vice President of Self-Advocates of Indiana. I sit on several committees about disability and self-advocacy. I also lead my local self-advocacy group.

I am passionate about equal rights for people with disabilities. I spend a lot of time speaking up about issues that affect us.

My host organization:



Self-Advocates of Indiana (SAI) is a statewide advocacy organization led by and for people with disabilities. We speak out, educate, and advocate for equal rights, respect, and inclusion for all in the community. More information can be found at www.saind.org.

Why this is important to me:

This issue is personal to me because I have been the victim of sexual violence. I was five when I was abused by my dad. What my dad did to me has caused issues like Post Traumatic Stress Disorder (PTSD). These issues still affect me as an adult.

A few years ago, I was in an abusive relationship. My friends and family helped me realize the relationship was not safe. They helped me get out of it. I know these experiences are not my fault. It is important that people with disabilities know what healthy and unhealthy relationships look like. We also need to learn how to advocate for ourselves to get out these types of unsafe situations.



WORDS TO KNOW

Words to Know

Sexual Violence: Sexual violence is any unwanted or forced sexual touching or activity. It covers many crimes like rape, sexual assault, and sexual abuse. (GMSA & RAINN)

Consent: Consent means getting a “yes” from someone before touching or sexual activity. The “yes” must be freely chosen.

- No lies
- No threats
- No pressure
- No force
- No bribes

A person can change their “yes” to “no” at any time. (GMSA)

Sexual Assault: Sexual contact or behavior that occurs without a yes. This includes forcing someone to do sexual acts that someone does not want. (RAINN)

Domestic/Intimate Partner Violence: Domestic Violence can happen in personal relationships. Abusers can be a spouse, partner, a family member or caregiver. The abuser has power and control over the person.

Domestic Violence can be:

- Physical like hitting or shoving
- Emotional like name calling or yelling
- Misusing a person’s money
- Taking away things a person needs such as medication, talking machine, or wheelchair
- Using threats
- Destroying property



Research

Research

Sexual violence has been talked about a lot in the news over the past year with the “Me Too” movement. These conversations have not involved people with disabilities.

People with disabilities are more likely to experience sexual violence than people without disabilities.

Here are some things I learned:

- People with disabilities are 7 times more likely to be sexually assaulted than people without disabilities (The Arc U.S.)
- Nearly 90% of women with intellectual or developmental disabilities experience sexual assault during their lifetime (The Arc U.S.)
- These crimes go mostly unrecognized, unprosecuted and unpunished (NPR)
- People with disabilities are even more likely to be abused by someone they know (The Justice Department)
- From more than 500 cases of suspected abuse in 2016 (NPR):
 - 42%--other people with intellectual disabilities
 - 14%--staff
 - 12%--relatives
 - 11%--friends



Risk Factors

People with disabilities are at a higher risk to become a victim of sexual violence. I learned that people with disabilities have many risk factors.



Risk Factors are things that make it more likely for a person to experience violence. (CDC)

Risk Factors for people with disabilities include:

- The false idea that people with intellectual disabilities are not sexual
- Need help from caregivers for basic needs like bathing and using the bathroom
- Lack of sexual education
- Unable to verbally communicate or speak clearly
- May not know the name of their body parts or what is happening to them
- Taught to obey rules
- Have not developed self-advocacy skills
- Staff turnover
 - People come in and out of their lives
- Guardians or providers have too much control
 - Self-Advocate may feel powerless in a bad situation
- Don't know how to make decisions or not given the chance

(Risk Factors from The Arc U.S., NPR, and the Arc's Center for Criminal Justice)

Preventative Factors

Preventive Factors are things that make it less likely that people will experience violence or commit violence in the first place. (CDC)

Important Preventative Factors include:

- Safe Housing
- Education
- Transportation
- Employment
- Financial independence
- Information to make informed choices
- Being connected in your community
- Positive relationships with friends and family
- Access to health care
- Problem-solving abilities
- Strong self-advocacy and self-determination skills



These preventative factors can keep violence from happening in the first place. They can also help support people if they do experience violence.

When we work to decrease sexual violence, we must look at all these things!

Decreasing risk factors and increasing preventative factors is called **Primary Prevention**.



Important Partners

Who Can Help?

It's important to look for other people that care about this issue. I had a lot of help from other people and groups that wanted to work on this problem too.

There are many groups you can reach out to get support.



Here are some ideas:

- Domestic Violence Organizations or shelters
- Sexual Violence Resource Centers
 - National Sexual Violence Resource Center has a directory of agencies in your state
 - [Agency Directory](#)
- Your state's Developmental Disabilities Council
- Your state's agency that oversees services for people with disabilities
- Your state's Quality Assurance Agency
 - These are the people that typically process any incident reports in your state.
- Your state Protection & Advocacy Organization
- Disability Advocacy Organizations
 - Your state chapter of The Arc
 - Centers for Independent Living
 - Self-Advocacy organizations

Making it work for you:

Write down 10 potential people or organizations that could help address the topic of sexual violence in your state

- | | |
|----------|-----------|
| 1. _____ | 6. _____ |
| 2. _____ | 7. _____ |
| 3. _____ | 8. _____ |
| 4. _____ | 9. _____ |
| 5. _____ | 10. _____ |

Our key partners:

- Indiana Coalition Against Domestic Violence
 - Helped us start the Statewide Abuse Prevention Taskforce
 - Provided training on Primary Violence Prevention
 - Helped us develop handouts and resources
 - Provided feedback about our survey
 - Provided funding to The Arc of Indiana to purchase healthy sexuality curriculum

- The Arc of Indiana & Self-Advocates of Indiana
 - Office space and technology
 - Staff support– Amanda Circle
 - Allowed me to assist with Sexuality Matters program, SAI’s healthy sexuality education program

- Indiana Coalition to End Sexual Assault (ICESA) & Multicultural Efforts to End Sexual Assault (MESA)
 - Asked me to present on a webinar about Guardianship and Consent.
 - [Guardianship and Consent Webinar](#)

Creating a Statewide Abuse Prevention Taskforce:

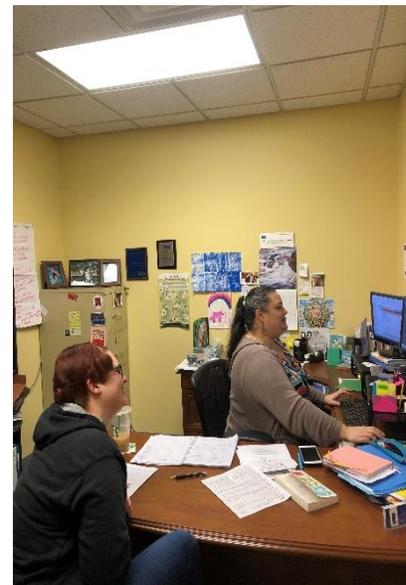
After meeting with other organizations, we realized Indiana needed a group of people focused on this issue. The Indiana Statewide Abuse Prevention Taskforce was created.

The mission of the taskforce is to support statewide efforts to prevent violence and enhance the independence and wellness for people with disabilities in Indiana.

You can find more information about how the taskforce was started and its goals by watching the [Taskforce Intro Video](#).

Steps to creating the taskforce:

1. Partnered with our state Domestic Violence Coalition
2. We talked about who would we should invite to be on the taskforce
3. We sent out an e-mail invitation to an informational meeting
4. We had the first meeting and discussed why this was important
5. Discussed what we wanted the taskforce to do



A lot of the people on the taskforce don't normally work together. We invited people from service providers, government agencies, violence prevention organizations, and self-advocacy groups.

It was helpful to have different perspectives

How to start your own taskforce:

1. Make a list of all the people and organizations that you think might care about this topic
2. Let them know why you want to form a taskforce
3. Find a place and time to meet
4. Get everyone together
5. Create an agenda or a list of things you want to talk about
6. Ask for their opinion on this topic and how it affects them personally or the people they serve
7. Create goals as a taskforce
 - You don't just want to talk about it, you want to do something!
 - Decide what to focus on—you can't do everything!
 - You could focus on educating people in your state about this problem or on advocating for a policy that needs to change
 - Create committees
8. Make sure that people with disabilities are on your taskforce and that their voices are being heard
9. Keep meeting because you won't get everything done in one meeting

Who could you invite to your taskforce?



Educating Self-Advocates

Knowledge is Power

It's important to educate self-advocates about this issue and make sure they know about their rights.

First, I had to find out what people with disabilities knew and wanted to know.

Focus Group

I am the vice president of our state self-advocacy organization. Our board has 26 members from around the state. My fellow board members helped me with my project.

I met with this group at our board meetings. I also presented information about my project to them at our December 2018 Board meeting.



Some of the questions that I asked the board:

- Do you think this is a problem in Indiana? Why?
- Do you feel confident that you know who to talk to or how to report if something happens?
- What do you think should be done to decrease this problem?
- How confident are you that you could identify if you were a victim of sexual violence?
- Do you have people in your life that you trust to ask questions about sex, relationships, your body?

Who could you invite to be in your focus group?

Survey for Self-Advocates

I created a survey for individuals with disabilities using Survey Monkey.

[Survey Monkey](#) is online survey tool that can help you collect information. It even has some accessibility features like allowing you to use pictures as answer choices.

The goal of my survey was to gather information about what people already know and what they wanted to learn.

Distributing the survey:

My host organization helped by sending this survey out to our self-advocate groups.

I handed out surveys and handouts at our annual Self-Advocates of Indiana conference.



Survey Questions:

My survey questions can be found on page 27 of the handouts section of this toolkit.

You can use these questions or change them to fit your needs.

What I learned from the survey:

- People wanted more information about getting married and having children
- People wanted more information about different types of relationships and moving from friends to a romantic relationship
- Most participants said they did have a trusted person that they could go to if they had questions
- Participants were able to identify examples of consent

Handouts

Working with our partners at Indiana Coalition Against Domestic Violence, I put together a few different handouts with information for self-advocates.

Sexual Violence Resources (pg. 31)

This handout has information about sexual violence.

- Where to go for support or resources.
- Provides tips for friends or family members of individuals who have experienced sexual violence.
- This resource is specific to Indiana but can be changed to fit the resources in your state.

Sexual Self-Advocacy Bill of Rights (pg. 33)

Self-Advocates of Indiana has a resource called the Self-Advocacy Bill of Rights. It talks about the rights of people with disabilities to make choices and live the life they want. I wanted to create something similar for sexual self-advocacy.

This handout can be used to teach self-advocates about their rights and sexual self-advocacy. It can also be used to talk with parents or providers to help them understand what people with disabilities want and need when it comes to sexuality.

Sexuality Education Program

The survey showed that people with disabilities wanted more information about sexuality and relationships.

People with disabilities don't always have access to the same sexuality education that people without disabilities have.

People with disabilities want to learn about sexuality so that they can make important choices.

SAI is creating a program to provide sexuality education. The goal is to educate our chapter members. I have helped develop the program and will be one of the sexuality educators.

There are many different tools available to teach this topic. Please decide what works for your group.

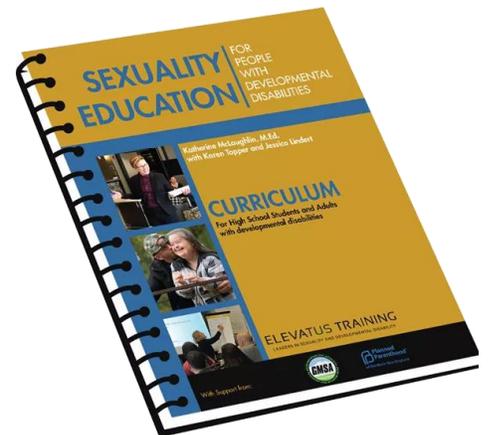
Self-Advocates of Indiana is using the curriculum "Sexuality Education for People with Developmental Disabilities" by [Elevatus Training](#).

We chose this curriculum because:

- Self-Advocates helped create it
- It's created to be taught by self-advocates and a support person
- It's easy to understand
- Elevatus Training has a series of online videos to help train your educators.

Other options:

- [Advocates for Youth Curriculum](#)
- [FLASH Curriculum](#)



Other Educational Initiatives

A View From My Window

Michelle Fischer is a self-advocate and hosts a podcast for The Arc of Indiana called “A View From My Window”.

I sat down with Michelle to talk about my project and share some of the things I learned.

You can find this podcast and her others at [A View From My Window](#).



Disability Justice Webinar Series

In partnership with Indiana Coalition Against Domestic Violence, I participated in a webinar about disability and consent.

The webinar can be found here: [Disability & Consent Webinar](#)



Changing Policies

Protective Policies

It is important to look at the policies that are in place to help protect individuals from sexual violence.

Do provider agencies have policies to protect the people they serve?

What are your State's policies for reporting incidents?

Does your self-advocacy organization have a policy to make sure people feel safe during your meetings and events?

Agency Policies:

I created a survey for Direct Support Professionals and agencies about their organizational policies. The results showed:

- Most agencies do have policies and staff are trained on them
- The individuals who are served may not be aware of the policies
- Some of the providers don't feel confident in handling suspected abuse situations
- Survey questions on pg. 34

Self-Advocacy Organizational Policy:

Self-Advocates of Indiana did not have a formal policy to help protect individuals who may experience abuse.

With the help of the SAI Board of Directors, we developed a SAI Values Statement. All board members will have to agree to these values when elected. This statement outlines:

- How we want to work together
- How to create a safe and respectful environment
- Sexual conduct policies



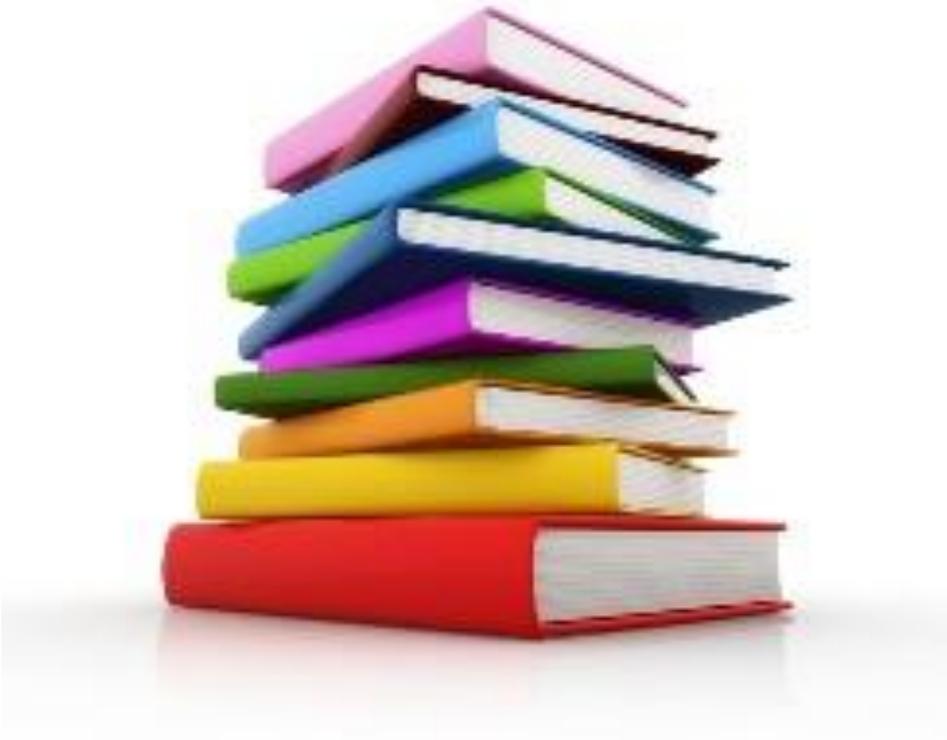
What's Next

How are we continuing the work?

Change doesn't happen overtime. Although we accomplished a lot during my year-long fellowship, there is still a lot to do.

I plan to continue to work on this issue.

- The Statewide Abuse Prevention Taskforce will continue to meet regularly
- I have been offered a consulting position with Indiana Coalition Against Domestic Violence
 - Working on a blog post about consent
 - Providing self-advocate feedback
- Self-Advocates of Indiana will be reviewing our by-laws over the next year. We will be adding in a full sexual violence policy to the by-laws and handbook
- Continue to partner with The Arc of Indiana to provide sexuality education



Resources & Handouts

Resources

The Arc of the United States

[Talk About Sexual Violence--Final Report](#)

[Talk About Sexual Violence Resources](#)

[People with Intellectual Disabilities and Sexual Violence](#)

National Public Radio (NPR)

[Abused & Betrayed Series](#)

Institute on Disability and Human Development (IDHD)

[In My Voice: Sexual Self-Advocacy](#)

[In My Voice: Sexual Self-Advocacy Video](#)

Centers for Disease Control

[Connecting the Dots](#)

Green Mountain Self-Advocates

[Peer-to-Peer Guide to Domestic and Sexual Violence](#)

RAINN (Rape, Abuse & Incest National Network)

[RAINN Website](#)

National Sexual Assault Telephone Hotline

1-800-656-HOPE (4673)

Sexuality Survey for Self-Advocates Questions

1. Have you received information about sexuality and relationships?
 - Yes
 - No
 - I'm not sure
2. Do you want to receive more information about sexuality and relationships?
 - Yes
 - No
 - I'm not sure
3. What information would you like to know? (Check all that apply)
 - Sexual Acts
 - Types of Relationships (strangers, friends, couples)
 - Body Parts
 - What a good relationship looks like
 - How to prevent pregnancy and sexually transmitted infections
 - Public Places and Private Places
 - What a bad relationship looks like
 - How to tell if you have been abused
 - Getting married and having children
 - Other (please tell us what you would like to know)_____
4. Where do you get your information about sexuality or relationships? (Check all that apply)
 - Family
 - Friends
 - School
 - Sex Education Class
 - Staff or Caregiver
 - Television
 - Magazine
 - Pornography
 - Internet
 - Other (please specify) _____

5. Do you know how to prevent pregnancy and sexually transmitted diseases?
- Yes
 - No
 - I'm not sure
6. Are you supported to have relationships?
- Yes
 - No
 - I'm not sure
7. Are you supported to have sexual relationships?
- Yes
 - No
 - I'm not sure
8. Can you get birth control if you wanted it? (condoms, the pill, Plan B, or other)
- Yes
 - No
 - I'm not sure
9. Do you have someone to talk to if you have questions about sex?
- Yes
 - No
 - I'm not sure
10. Do you have someone to talk to if you have questions about romantic relationships?
- Yes
 - No
 - I'm not sure
11. Do you have a person to talk to when you have questions about your body and sexual parts?
- Yes
 - No
 - I'm not sure
12. Do you have private space in your home where you can be alone?
- Yes
 - No
 - I'm not sure

13. Sexual Violence is any unwanted or forced sexual touching or activity. Sexual harassment is any comment, gesture, or sexual hint that is unwanted.

Do you have a person to talk to if you experience sexual violence or sexual harassment?

- Yes
- No
- I'm not sure

Examples of Consent (*examples from Sexuality Education for People with Developmental Disabilities by Elevatus Training*)

Sexual Activity must be consensual. Consensual means that both people must say "yes" to doing the sexual activity.

Consent is getting a "yes".

The "yes" must be freely given, which means:

- No lies
- No threats
- No force
- No bribes
- No pressure
- Both people can change their mind at any time

Read the stories below and choose if the activity was consensual between both people.

14. Drew see Allison on the street and thinks she is very pretty. Drew goes up to Allison and touches her breasts.

Did Allison consent to be touched?

- Yes
- No
- I'm not sure

15. One person asks the other if they want to have sexual intercourse.
The other person says yes.
They have sex and enjoy it.

Did both people consent to have sexual intercourse?

- Yes
- No
- I'm not sure

16. You are with your sweetheart and you are kissing.
You want more touch, so you move your hand down to his or her
genitals (sexual parts).
He or she stops your hand and pushes it away.

Did he or she consent to you touching his or her sexual parts?

- Yes
- No
- I'm not sure

Sexual Violence Resources

Words to Know

Sexual violence is any unwanted or forced sexual touching or activity.

- Brushing against the person in a sexual way
- Talking about sex or your body in a sexual way
- Forced kissing
- Removing clothes without asking
- Forcing a person to look at pornography
- Sexual touching/acts you are not comfortable with

Domestic Violence happens in personal relationships. Abusers can be a husband or wife, a partner, a boyfriend or girlfriend, a family member or caregiver. The abuser uses power over another person to control that person. Domestic violence can include:

- Physical (hitting, shoving etc.)
- Emotional (name calling, yelling etc.)
- Misusing a person's money
- Taking away things needed to survive such as medication, talking machine, wheelchair, etc.
- Using threats
- Destroying property

What you can do if you experience Sexual or Domestic Violence

- **If you are in a dangerous situation, go to a safe place and contact 9-1-1**
- Call a Sexual Assault Service Provider
 - In Indiana, you can find one in your county at Indiana Coalition to End Sexual Assault's directory: www.indianacesa.org
 - You can also call the National Sexual Assault Hotline at 800-656-HOPE (4673)
- Call a Domestic Violence Services Provider
 - National Domestic Violence Hotline 800-332-7385
 - Indiana Coalition Against Domestic Violence, 317-917-3685, can provide referrals to programs in your county.

- You can choose to receive medical attention
 - At the hospital you will receive a medical exam (“rape kit”) which will help collect and preserve any physical evidence of the assault
 - You can do this whether or not you want to go to the police right away
- You can call the police
 - You may choose to file a report
 - You do not have to file a report even if the police come to the scene
- You may choose to tell a friend or family member
 - If this person is a Mandatory Reporter, they will have to report it to Adult Protective Services

How to help a friend who has experienced sexual violence

- Be a good listener—don’t talk too much
- Show respect, don’t judge
- Keep your focus on your friend
- Educate and empower—help them make decisions for themselves
- Offer to go with them to the hospital or police if they choose to report
- Help them find a trained sexual assault or domestic violence advocate
- If you are a Mandated Reporter, you must report suspected abuse, including sexual abuse to Adult Protective Services 1-800-992-6978

Additional Resources

Indiana Coalition Against Domestic Violence: www.icadvinc.org

Indiana Coalition to End Sexual Assault: www.indianacesa.org

Information for this handout provided by Indiana Coalition to End Sexual Assault and the Green Mountain Self-Advocates of Vermont

Sexual Self-Advocacy Bill of Rights

What is Sexual Self-Advocacy?

Making choices and speaking about what you need and want when it comes to relationships and sexuality.

My rights:

I have the right to be a sexual human being

I have the right to be treated like an adult

I have the right to speak up and express my sexuality

I have the freedom to be who I am (LGBTQ+) without fear of harassment or harm

I have the right to make mistakes

I have the right to receive information about sex that I can understand

I have the right to decide what is right and safe for me

I have a right to private space and private time

I have a right to ask questions without someone making decisions for me

I have the right to ask for new staff or caregivers if I do not feel comfortable

I have the right to feel safe in my home and community

I have the right to access sexual health care

I have right to have safe and secure relationships based on respect

I have the right to not be pressured, controlled, or manipulated by a partner

I have the right to say NO to anything I am not comfortable with

I have the right to say no to any kind of touch

I have the right to not let people disrespect me, call me names, put me down, or make me feel bad about myself

Survey for Providers & DSPs

1. Does your agency have written policies about reporting of suspected abuse, neglect, or exploitation?
 - Yes
 - No
 - I'm not sure
2. Are all employees trained on this policy?
 - Yes
 - No
 - I'm not sure
3. Are you individuals you served trained on this policy?
 - Yes
 - No
 - I'm not sure
4. Does your agency have a whistleblower policy, protecting clients or staff who come forward with suspected abuse?
 - Yes
 - No
 - I'm not sure
5. In the past five years, how many times has a participant reported to you or someone you directly supervise that they have been abused?
 - More than 5 times
 - Less than 3 times
 - Less than 2 times
 - Once
 - Never
6. How confident did you feel about handling the situation?
 - Extremely confident
 - Very confident
 - Somewhat confident
 - Not so confident
 - Not at all confident

7. Does your agency have policies allowing individual you serve to participate in consensual sexual activities?
- Yes
 - No
 - I'm not sure
8. In your agency's residential settings, do your policies allow individuals you serve to have a private space and private time?
- Yes
 - No
 - I'm not sure
9. How comfortable are you talking about sexuality to individuals you serve?
- Very comfortable
 - Somewhat comfortable
 - Not very comfortable
 - Not comfortable at all
10. Does your agency provide access to resources for people who want to learn about sexuality?
- Yes
 - No
 - I'm not sure
11. If an individual you served told you they had been abused or been a witness to abuse, who would you tell?
-
12. Are you a mandated reporter?
- Yes
 - No
 - I'm not sure
13. In which settings do you provide services? (Select all that apply)
- Community
 - In an individual's personal home or family home
 - At a day program or workshop
 - In an agency residential setting
 - On a job site
 - Other _____



Self-Advocates of Indiana

Board Member Values Statement

Self-Advocates of Indiana's vision is to speak out and advocate for equal rights, respect and inclusion for all in the community.

Self-Advocates of Indiana (SAI) is committed to creating and keeping a safe, stable and nurturing environment where all members feel safe to work, learn and grow. As part of this commitment, SAI will promote a safe, equal, and supportive environment between members of SAI and will prohibit all forms of violence, harassment, discrimination, or disrespect.

What is a Safe, Stable, and Nurturing Environment?

- Based on care, affection, friendship, and equality for all individuals
- All relationships involve disagreements and ups and downs, but in safe, stable, and nurturing relationships, everyone gets to be themselves.
- All members deserve to have their own thoughts, opinions, interests, friends and intimate relationships.
- Safe, Stable and Nurturing relationships are respectful.
- Respectful relationships feel fun, they feel safe, they feel mutual.

This policy applies to all Self-Advocates of Indiana sponsored activities, including any overnight stays or travel sponsored by SAI. The policy also applies to contact through technology, cell phones, or social media if it has a negative effect on the self-advocate community or on any member's ability to participate in SAI activities

In order to create a safe, stable, and nurturing environment at all SAI activities, as a member of the Self-Advocates of Indiana Board of Directors, I will:

- Treat all SAI members, staff, and people with whom SAI has business relationships with respect, courtesy, and dignity.
- Help create a welcoming, respectful, and comfortable environment for all.
- Not use abusive or harmful language, including harmful language about a person's race, ethnicity, gender identity, sexual orientation, disability, or religion
- Never make unwanted verbal, sexual, or physical contact with other members
- I will NOT harass, threaten, embarrass, or insult others.
- Follow all rules and policies determined by the Self-Advocates of Indiana Board of Directors and its By-Laws.
- Behave in a way that is safe, and does not put myself or others at risk of physical harm or legal action
- Recognize that as a leader of SAI, my actions represent the Self-Advocates of Indiana organization
- Respect the confidentiality of my fellow SAI members
- Make sure that everyone is included, and no one is left out or left behind
- Never use physical violence or threaten physical violence upon another member of SAI
- Show up ready to work and do my best
- Actively participate and uphold any assigned responsibilities

Signature

Date



SARTAC

Self Advocacy and Beyond

This publication is supported in part by a cooperative agreement from the Administration on Intellectual and Developmental Disabilities, Administration for Community Living, U.S. Department of Health and Human Services. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration on Intellectual and Developmental Disabilities policy.

The Self Advocacy Resource and Technical Assistance Center (SARTAC) seeks to strengthen the self-advocacy movement by supporting self-advocacy organizations to grow in diversity and leadership. The resource center is a project of Self Advocates Becoming Empowered (SABE), the oldest national self-advocacy organization in the country. SARTAC is a Developmental Disabilities Project of National Significance, funded by the Administration for Community Living – Administration on Intellectual and Developmental Disabilities (AIDD). The information in this manual was written to provide guidance for self-advocates and their allies to assist in understanding policy issues affecting their lives. It is not to be used to determine a person's legal rights or an organization's legal responsibilities under Section 504 of the Rehabilitation Act of 1973, as amended; the Americans with Disability Act of 1990, as amended or any other federal, state or local laws written to protect the rights of people with disabilities.