

PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITY EXPERIENCING ABUSE: TIPS, TOOLS AND STRATEGIES FOR PROVIDERS

The Arc's National Center on Criminal Justice and Disability
Talk About Sexual Violence Project

Webinar Series – Webinar 3 of 4
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Presenters

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Overview of Today's Webinar

- Using recent survey data, participants will learn how pervasive attitudinal barriers are in health care
- Participants will learn how providers can practice effective ways to interact and communicate with people with disabilities
- Participants will understand the important role of peer support and coalition building as two promising practices that can reduce bias among health care providers

Supported Decision Making

- Small studies report positive outcomes with many saying they were more confident, happier and better able to do what they want
- Gained momentum with 2006 approval of the UN Convention on Rights of Persons with Disabilities
- Making your own decisions is at the heart of what it means to be a person, including a patient or survivor

National Center on Criminal Justice and Disability® (NCCJD)



- Created in 2013 with support from the Bureau of Justice Assistance
- Mission: Advocate at the intersection of criminal justice reform and the advancement of disability rights
- Target audiences: Disability advocates, criminal justice professionals, people with IDD and The Arc's chapter network

National Center on Criminal Justice and Disability



Training and technical assistance

- Pathways to Justice®
www.nccjdpathwaystojustice.org
- Community-based program that creates Disability Response Teams (or DRTs)



Information and referral

- For people with disabilities and their families as well as criminal justice and allied professionals
- <https://thearc.org/our-initiatives/criminal-justice/>



Resource collection and creation

- Policy briefs, fact sheets, other publications



Education

- Social media, webinars, and conferences

Case Scenario: Kecia Meets with Her Doctor

VIDEO: https://www.youtube.com/watch?v=_3gFXB8yeLU&t=1s

- The doctor and nurse had gentle tones to their voices and made eye contact with Kecia
- They were genuinely concerned about Kecia's bruised arm and infection
- The doctor asked Kecia's caregiver to step outside the examination room
- The doctor used a picture chart to help video Kecia articulate where she had gotten abused
- Even though Kecia was traumatized Kecia did not appear re-victimized by her doctor's visit
- Both the doctor and nurse used everyday language, so Kecia could understand what was going on

In the video the nurse hands Kecia a card with resources.

What can you do if the resource is not accessible?

Doctors Admit They Don't Want Patients with Disabilities

You want the doctor to be on your side

- Patients using wheelchairs were told to go to a supermarket, a grain elevator, a cattle processing plant or a zoo to be weighed
- Disabled patients take too much time; disrupts the clinic flow
- All went well until person mentioned he had a wheelchair, all of the sudden his appointment was canceled
- "Some will find every excuse to not see you."
- "I really don't know what to do with you, maybe you should go elsewhere."

Source: <https://www.nytimes.com/2022/10/19/health/doctors-patients-disabilities.html>

Bias in Healthcare: View from Survivors

Question 1:

What have you experienced and what have others shared with you regarding bias or being stereotyped?

- Kecia (feeling invisible when focus is on my support person)
- Patty (making assumptions about me, I'm not given clear directions)

Bias in Healthcare: View from Survivors (cont.)

Question 2:

What looks like bias in health care? Can you give more examples? What about assuming competence?

- Kecia (competency and making informed decisions)
- Patty (feeling ignored and not understood)

Bias in Healthcare: View from Survivors (cont.)

How does bias influence how you are treated by health care professionals?

- Lack of Respect
- Devaluation
- Discrimination
- Lack of training
- Disability vs trauma focus (the focus is on my disability, not the trauma)

Key Takeaways: What is Needed?

Kecia:

- Open attitude and willingness to learn
- Listen to the patient
- Understand the importance of accessibility

Patty:

- Learn Disability 101
- Provide enough time
- Learn about and use trauma-informed approaches
- Get training that includes survivors as part of the team



Bias in Healthcare: Solutions from Survivors with Disabilities

Solutions from Survivors: Attitudinal Barriers

Patty

- Respect us as equals, provide training, “Nothing About Us without Us”

Kecia

- Communication, using culturally sensitive language, focus on ability and capacity, not disability

Solutions from Survivors: Effective Communication

Patty

- Encourage survivors to learn coping skills, help them understand they have choices

Kecia

- Use accessible formats to communicate (captions, icons and pictures, ASL, universal design), this promotes equality for everyone

Individual Impact – What Can One Person Do?

- Imagine you are talking to your doctor after a sexual assault. What does the doctor need to say when explaining about taking medication?
 - Kecia: I stopped using medicine and got very sick. Consider using teach-back method
 - Patty: Doctors explain what happens when you take a medication. They need to tell you about side effects. They should give you choices. If the meds work, that's fine. If not, then you should have other choices.

Accommodations

What kinds of accommodations can help you when making health care decisions?

Patty

- I ask my doctor to write everything down so I can share with family member or support person. I ask that they use everyday language.

Kecia

- Supported decision-making really helps – I talk with knowledgeable support people and ask questions. I then make my own decision and it feels empowering.

Collective Impact – What Can We Do Together?

Peers are creating and building diverse coalitions, moving from being contributors to leaders to creators

- Arizona Network on Sexual Violence and IDD (AZ)
- Silence = Violence Network (CA)
- Peer Support Network (MA and national)

Bias in Healthcare: Key Lessons Learned from Survivor Self-Advocates

- A new approach – from **peer to professional leader**.
- Peer led coalition/network
- Learn about ableism and why it is a key barrier to having equity
- Expert facilitation, not someone who speaks for the person
- Training for professionals, *especially disability 101*
- Things are getting better but there is more to do

How Are You Making a Positive Impact?

- Patty
 - Saying THANK YOU matters!
- Kecia
 - Telling health care providers I deeply appreciate them



Questions?

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THANK
YOU

