BRAIN HEALTH AND TRAUMA-INFORMED CARE FOR PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

The Arc’s National Center on Criminal Justice and Disability and the HealthMatters™ Program
Webinar Series – Webinar 1 of 4 - March 1, 2023
Presenters

Leigh Ann Davis  
Senior Director, Disability & Justice Initiatives, The Arc of the United States

Jaime Suvak, LMHC, Ph.D.  
Student, School of Global Inclusion and Social Development, UMASS

Patty Quatieri  
Peer Support Leader with Sexual Assault Response Unit at Disabled Persons Protection Commission of MA

Kecia Weller  
Co-Chair Peer Support Network, Advocate Advisor with CA State Rehabilitation Council and UCLA Tarjan Center.
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
  • Work on both victim/witness issues and on issues facing those who are charged with crimes
• Broad portfolio of projects and contracts from the federal government and foundations totaling over $500k
• 3 full-time staff and 1 part time consultant (Senior Director, Senior Program Associate and NCCJD Consultant)
• 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
NCCJD’s Projects & Initiatives

• Academic Training Project – Developing a national training for law enforcement on Mental Health and IDD
• Project Home Safe – Addresses wandering of people with autism and lead by International Assoc of Chiefs of Police
• Talk About Sexual Violence
• Arizona Sexual Violence & Disability Network
• Open Society Foundations (international knowledge hub)
• Contracts (Council of State Governments Justice Center)
• NCCJD’s Community of Practice for The Arc’s chapter network
Brain Health and Trauma

• Disproportionate impact of trauma among people with intellectual and developmental disability (IDD) across the lifespan
  o People with IDD of all ages are more likely to experience trauma than peers without disabilities*
  o Higher risk of maltreatment increases risk for trauma for people with IDD
  o Trauma includes emotional, physical, sexual abuse, neglect, exploitation

• Trauma- and resilience-informed healthcare systems can improve:
  o Healthcare engagement
  o Treatment involvement
  o Health outcomes

Preventing Violence, Abuse, Neglect, and Exploitation of People with IDD

• 2021 Webinar from Healthy Brain Webinar Series
• Includes webinar recording, PowerPoints and links to resources
• Content includes:
  • Identifying the range of abuse and neglect people with intellectual and developmental disabilities experience
  • Learning how to talk to people with IDD about trauma

• HealthMatters YouTube channel
  https://www.youtube.com/@healthmattersprogram4218
Purpose of this webinar series

1. Highlight discriminatory practices and implicit bias in healthcare settings and encourage use of trauma-informed care strategies

2. Learn from national peer advocate survivors, allies, and healthcare providers about brain health and trauma-informed care
Overview of Today’s Webinar

• Trauma affects people with IDD throughout their lives and as they age

• Accessing trauma-informed care is a major challenge for people with IDD

• Healthcare providers, social service providers, and community supports may have biases about people with disability that interfere with providing acceptable care

• This webinar reviews the impact of ableism in healthcare for people with IDD through case-based learning
Trauma Definition from SAMHSA

- Individual trauma can result from an event, series of events, or set of circumstances as physically or emotionally harmful, or life-threatening.
- Lasting adverse effects on the individual’s functioning and mental, physical, social, emotional, or spiritual well-being” *
- Trauma affects the brain and body which can cause, for example:
  - Behavioral: depression, panic attacks, poor concentration
  - Physical: headaches, stomach issues including nausea and trouble eating
  - Sleeping issues
  - Increased risk of developing dementia

The Impact of Trauma is Widespread

**ABUSE**
- Physical
- Emotional
- Sexual

**NEGLECT**
- Physical
- Emotional

**HOUSEHOLD DYSFUNCTION**
- Mental Illness
- Incarcerated Relative
- Mother treated violently
- Substance Abuse
- Divorce

Source: Centers for Disease Control and Prevention
Credit: Robert Wood Johnson Foundation
Talk About Sexual Violence – An Overview

• Easy-to-use training tools for Health Care Providers
  • Outreach to HCPs
  • Increase patient-centered conversations
  • Increase reporting of sexual violence
  • Decrease discomfort talking about sexual violence with patients with IDD
Talk About Sexual Violence Core Values: Listen & Believe

James Goes to the Doctor

This three-minute video illustrates a medical appointment where James, a male survivor, visits his doctor and discloses that he has recently experienced sexual violence.

Men can be raped too
It's not our fault
Rape is a crime and must be reported
There are people who want to help

Kecia Meets With Her Doctor

This three-minute video illustrates a medical appointment where Kecia visits his doctor and discloses that she has recently experienced sexual violence.
We need to talk about sexual violence and end the silent epidemic of abuse!

Kecia Weller

People with intellectual and developmental disabilities deserve a life free from abuse. Abuse is too often ignored or excused!

James Meadours
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.

**What would you do to promote continuity of care?**

**Definition:** Continuity of Care is an organized and carefully coordinated process essential to high-quality patient/client care which involves the patient, family, and an interdisciplinary team working together to facilitate the transition of the patient/client from one level of care to another.
Trauma-Informed Approach

Jaime Suvak, LMHC, Ph.D.
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6 GUIDING PRINCIPLES TO A TRAUMA-INFORMED APPROACH

The CDC’s Center for Preparedness and Response (CPR), in collaboration with SAMHSA’s National Center for Trauma-Informed Care (NCTIC), developed and led a new training for CPR employees about the role of trauma-informed care during public health emergencies. The training aimed to increase responder awareness of the impact that trauma can have in the communities where they work.

Participants learned SAMHSA’S six principles that guide a trauma-informed approach, including:

1. SAFETY
2. TRUSTWORTHINESS & TRANSPARENCY
3. PEER SUPPORT
4. COLLABORATION & MUTUALITY
5. EMPOWERMENT VOICE & CHOICE
6. CULTURAL, HISTORICAL, & GENDER ISSUES

Adopting a trauma-informed approach is not accomplished through any single particular technique or checklist. It requires constant attention, caring awareness, sensitivity, and possibly a cultural change at an organizational level. On-going internal organizational assessment and quality improvement, as well as engagement with community stakeholders, will help to imbed this approach which can be augmented with organizational development and practice improvement. The training provided by CPR and NCTIC was the first step for CDC to view emergency preparedness and response through a trauma-informed lens.
Using a Trauma-Informed Approach

- Review agency policy and procedures
- Provide training to all staff
- Screen for trauma
- Build relationships
- Understand culture and community
- Utilize peer models
- Engage trauma survivors in all aspects of the work
- Develop, Innovate, Collaborate

Source: “Treating the Hidden Wounds: Trauma Treatment & Mental Health Recovery for Victims of Human Trafficking” by Heather J. Clawson, Ph.D., Amy Salomon, Ph.D., and Lisa Goldblatt Grace, LICSW, MPH.
Conversation with Kecia

- Describe the doctor’s appointment that is described in the case scenario
- Describe what your real-life doctor’s appointment
- What was different about the appointments?
- How did you feel during and after your actual appointment?
Conversation with Patty

- What was it like when you reported abuse to your doctor at your appointment?
- Do you think you were treated in a different way because of your disabilities?
- What happened after the appointment?
- Did you get the help you needed?
Interviews with Kecia and Patty

• As national peer advocates, what would you recommend to health care professionals?

I would advocate for:

• Using trauma informed practices
• Educating health care professionals on the needs of people with different types of disabilities
• Spending more time with the survivor
• Being patient because it is hard to talk about sexual assault
• Having resources available that are easy to understand
• Using Teach Back at the end of the appointment
• Including a health care advocate at appointments
Recommendations and Discussion

What’s better now?

- **Advocacy**: Survivors speak up now, they are being heard, and starting a national network
- **Healthcare**: There is a SANE nurse in ER rooms, more training for doctors, more trauma-informed therapists
- **APS**: They are open to learning about how to work with us
- **Public**: More information is in the news, people are learning how often it is happening
Recommendations (continued)

Ways healthcare can improve:

• Listen, be patient, believe
• Remind the patient what is important to do before they leave the appointment
• Ask if the person feels safe before the appointment ends
• Learn about trauma informed practices and use them
Webinar Series: Brain Health and Trauma-Informed Care for People with Intellectual and Developmental Disabilities

- March 8, 2023
  Brain Health and Trauma among People with Intellectual and Developmental Disability: Systemic Bias and Ableism in Healthcare

- April 26, 2023

- May 10, 2023

LINK: UIC WebEx Site - Register Program
Contact Information

• Talk About Sexual Violence
  www.talkaboutsexualviolence.org

• Leigh Ann Davis - LDavis@thearc.org
• Mark Starford – Mark@brcenter.org
• Kecia Weller – Abuseprevention7@gmail.com
• James Meadours - jetsttr31@icloud.com
• Patty Quatieri - Patricia.Quatieri@mass.gov
• Jamie Suvak - jsuvak@me.com

• Visit NCCJD® online
  www.thearc.org/NCCJD
THANK YOU