# The **Board** Resource Center

Making Complex Ideas Simples

# Talk About Sexual Violence – Final Report

## September 2017

# **Board Resource Center**Mark Starford & Charlene Jones

# The Arc's National Center on Criminal Justice and Disability®

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<u>Talk About Sexual Violence</u> was funded by the Special Hope Foundation and carried out by the Board Resource Center (BRC) and The Arc's National Center on Criminal Justice and Disability® (NCCJD). BRC held primary responsibility for facilitating advisory groups and producing project deliverables - training videos, tools and supplemental materials.

This report and project resources can be found online at: <a href="https://www.talkaboutsexualviolence.org">www.talkaboutsexualviolence.org</a>



#### **Board Resource Center**

Since 1994, BRC has addressed educational and training needs for individuals and organizations that foster leadership, self-determination, and community inclusion. Focus areas include person-centered strategies and multi-media plain language products that increase informed decision-making, engagement in public policy making and advocacy. BRC makes products and training available and accessible to a broad range of audiences. More about our work is available online: <a href="https://www.brcenter.org">www.brcenter.org</a>.

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#### The Arc's National Center on Criminal Justice and Disability®

NCCJD® is a national clearinghouse for information and training that focuses on assisting people with intellectual and developmental disabilities (I/DD) who are victims, witnesses and suspects or offenders. Established in 2014, NCCJD partners with a broad spectrum of criminal justice professionals to create safer lives for people with I/DD who become involved in the criminal justice system. Our mission is to build strong, continual capacity of the criminal justice and disability services system to respond to gaps in existing services for people with disabilities, focusing on people with I/DD who remain a hidden population within the criminal justice system.

More about NCCJD's work, including our signature Pathways to Justice® training is available online: <a href="https://www.thearc.org/NCCJD">www.thearc.org/NCCJD</a> and <a href="https://www.nccjdpathwaystojustice.org">www.nccjdpathwaystojustice.org</a>

# **A Personal Story**

#### Kecia Weller



As a self and peer advocate who sits on boards and councils, I represent my community. I help advise on public policies that improve our lives. Most important, I want to help people with disabilities break through the fears and barriers that abuse brings.

My story is this. I met this man at a self-advocacy meeting and we had very similar hobbies. I invited him to my house to play chess. As soon as he entered my house, he started to kiss me and dragged me toward the couch where he proceeded to rape me. I called the police to report the rape and they investigated by interviewing this man who lied - telling them I wanted to have sex with him. I absolutely didn't want to have any sexual contact with him whatsoever. I also called my service agency for help and reported the rape to my case manager. She filled out a Special Incident Report, but did nothing to assist me with how to cope.

The system had totally failed me. As a result, I sank into a deep depression. It was only through years of specialized therapy that I can speak of the rape incident now. Today I am a sexual assault awareness and prevention advocate who helps others rise from abusive situations and become stronger, like I am.

I feel strongly that all of us have to be educated and have trusted friends who will help us have the courage to report people who take advantage of us. No one with disabilities should have to deal with sexual violence or abuse.\*

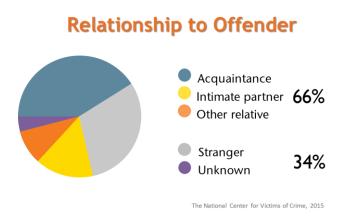
Let's work together to stop this epidemic!

<sup>\*</sup>See End Notes for sources that describe use of terms "sexual abuse and "sexual assault"

# **Background**

#### Need

Nationally, 1 in 5 women are sexually assaulted. However, women and girls with intellectual or developmental disabilities are four to ten times more likely to face sexual assault, with nearly 90 percent experiencing sexual assault during their lifetime. According to recent data from the Bureau of Justice Statistics, the rate of violent victimization (defined as rape or sexual assault) of people with disabilities is more than three times higher than the rate for people without disabilities.



Studies show that learned reliance on caregivers and authority figures, as well as confusion about what sexual assault is, allows this trend to continue. Sexual assault is often not reported because women with intellectual or developmental disabilities may not have a safe person to turn to for help.

With greater awareness of the prevalence of abuse and low health literacy, health care professionals can use effective communication strategies to offer a protected place where women with intellectual or developmental disabilities can talk openly about sexual assault.

#### Impact on Healthcare Delivery

Health care professionals who provide direct service and care to patients have unique opportunities to prevent or stop sexual assault. However, many professionals have not had experience talking about victimization with women with intellectual or developmental disabilities. In addition, most women with disabilities are unlikely to raise the topic of sexual violence on their own, often having limited health literacy and knowledge about what constitutes sexual assault or abuse.

Information needs to be attractive and easy to understand, with real life examples that people can relate to."

Participant

Health literacy is defined as "...the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions." Recent surveys revealed only 12 percent of adults have proficient skills to maintain health, prevent disease, and use the U.S. health care system. Because nearly 9

out of 10 adults may lack skills needed to manage their health, it is imperative that providers use patient care strategies that aim to address this lack of capacity. For health care providers to have meaningful conversations about sexual violence, training is needed to more effectively communicate with patients and to provide safe environments to share their experiences.

# **Purpose**

Health care providers hold key positions to prevent sexual violence and must work together with individuals with disabilities and their allies to ensure all patients are supported and served. Health care professionals are not expected to be the sole source of solutions and support, but simply listening, believing and directing the victim to local resources lays the groundwork for prevention. Using the *Talk About Sexual Violence* training materials will help build the capacity and confidence of primary care providers to discuss sexual assault with women who have intellectual or developmental disabilities.

#### Goals

The goal of *Talk about Sexual Violence* is to provide the much-needed tools that equip health care providers, women with intellectual or developmental disabilities, and their allies to communicate effectively about sexual violence and, more importantly, prevent it. To accomplish this, BRC was tasked with developing straightforward, easy-to-use training tools and supplemental materials to guide health care providers in supporting and facilitating conversations about sexual assault.

#### **Objectives**

- 1. Develop two short training videos
  - "How to Have the Conversation"
  - "Kecia Meets with Her Doctor"
- 2. Create supplemental materials:
  - Communication Strategies
    - Communication charts
    - Conversation tips
    - Referral card to support agencies
  - Sexual violence research and data
    - Community supports
    - Victims' rights
    - o Crimes against people with disabilities
  - Training Guide
- 3. Disseminate project resources and tools nationally to:
  - Health care provider groups, organizations and associations
  - California regional centers and provider associations
  - State and national disability advocacy organizations and associations
  - Self & peer advocacy groups
  - Persons with intellectual or developmental disabilities and families

# **Project Methods**

Consumer engagement is essential for success with all models of care delivery. Ensuring the presence of active end-user voices is especially important for populations with specialized needs, such as individuals with low literacy skills, seniors and people with disabilities. The formative approach that BRC uses underpins this person-centered focus and leads to outcomes shaped by needs and preferences of target audiences. It is aimed to guide the development or adaptation of programs and tools that lead to successful outcomes. BRC's work also emphasizes a "plain language" practice that underscores accessible and functional information for stakeholders to support informed decision making.

Talk about Sexual Violence was guided in partnership with an advisory group of social service and medical professionals as well as advocates, including a primary care



physician, disability service medical directors, self and peer advocates with intellectual or developmental disabilities, victims' rights and adult protective service providers, and a California developmental services regional center training officer. The group met three times and focused project objectives on a target audience

of primary care providers who see women with disabilities in their everyday practice.

The group meetings were designed as interactive sessions that used open-ended questions to explore content and plain language needs for development of project training videos and materials. They encouraged authentic exchange among members with two facilitators, followed by a review of tools in draft and final form.

# **Project Results**

#### **Outcomes**

Talking About Sexual Violence was designed by BRC and The Arc's NCCJD®. Both have missions that emphasize accessibility of information to empower people with intellectual or developmental disabilities. Their experience strongly suggests that ease of access to training and tools is key to success. The project was carried out with this in mind. It aims to improve care by giving professionals straightforward guidance when caring for female patients with who decide to discuss or disclose sexual assault.

#### **Deliverables**

Two short videos were produced, "How to Have the Conversation" and "Kecia Meets with Her Doctor", available in both English and Spanish. In addition, accompanying supplemental materials can be accessed online at <a href="https://www.talkaboutsexualviolence.org">www.talkaboutsexualviolence.org</a> and used for small group training sessions.

These include:

- 1. Training
  - Training guide
  - PowerPoint slides
- 2. Communication Strategies
  - Conversation tips
  - Referral card
  - Charts
    - o Body parts
    - o Expressions
    - Basic words
- 3. Research Data
  - Offender relationship
  - Crimes against people with disabilities

In addition, links to resources related to hotlines and support for crime victims, professional reporting responsibilities, patient-centered communication, and sexual assault prevention are also provided.

Dissemination of project tools has begun via extensive online distribution to health care provider organizations, disability advocacy groups, and California developmental service regional centers. Project tools and materials are available online through The Arc, housed under NCCJD, and dissemination will continue in the future. Utilization success is measured by tracking the number of users who access these online resources.

#### **Recommendations**

Talking about Sexual Violence Advisors offered recommendations for ongoing and next efforts in sexual assault prevention and victim support, these are included for future consideration.

#### 1. Increase mandated reporting of sexual assault

- Reduce fear of liability or retribution for healthcare professionals
- Increase public awareness and understanding of reporting process
- Train healthcare and social service providers to better recognize signs of sexual violence in people with Intellectual or developmental disabilities

#### 2. Increase victim (men and women) understanding of sexual violence

- Use short videos to introduce topic in comfortable and facilitated group settings
- Provide case managers with videos to begin conversation with "client and family"
- Create a plain-language overview and video about what sexual assault is, risks, victim resources
- Assist person(s) at risk to develop a safety plan and identify a go-to "safe" person
  - Regional Center Service Coordinators at an annual meeting
  - o Local and regional peer advocacy conferences
- Include prevention information, risk planning in Special Education curricula
- Introduce people with disabilities to law enforcement and visa-versa

## 3. Increase professional dialogue regarding prevention, reporting and victim support

- Engage Adult Protective Services and victims' right organizations
- Make presentations at professional conferences
  - Physicians, Nurses, Physician Assistants, APS, National Association of Social Workers, etc.
- Use electronic newsletters, networks via websites to disseminate information

- Create a smart phone app for easy reporting or photo-witnessing
- Create easy-to-use online information for "direct support" in-home professionals
- Provide training to care institutions and support agencies
- Target health care management organizations and providers (e.g., Kaiser, Sutter)
  - o In-house training platforms to share prevention information and project tools
- Use training specialist teams for Regional Centers with physicians and consumers
- Use faith community to share prevention information and resources
- Tap into campaigns already underway and learn from them
  - O Domestic violence, elder and child abuse, college sexual assault prevention
  - o Identify spokesperson to lead campaign of awareness and prevention
- Develop peer advocates to provide awareness and training: Train the Trainer

# **Acknowledgements**

The Arc's National Center on Criminal Justice and Disability® and Board Resource Center are grateful to the people and organizations that made this project possible. Due to the high rate of sexual victimization among people with intellectual and developmental disabilities, many victims suffer in silence unless someone notices the red flags of sexual violence and begins asking questions.

Thank you to Kecia Weller and Molly Kennedy for their willingness to openly talk about their personal experiences and spend countless hours creating training tools for the medical profession.

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### **End Notes**

- S.C. Ratzan, R.M. Parker (2000). "Introduction." In *National Library of Medicine Current Bibliographies in Medicine: Health Literacy*. Pub. No. CBM 2000-1.
- U.S. Department of Education National Center for Education Statistics (2006). *The Health Literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy.* (1993, 2003). *National Assessment of Adult Literacy.*
- J. Kimble (2002). "The Elements of Plain Language." *Michigan Bar Journal*, 81:44-45. U.S. Dept. of Education National Center for Education Statistics.

https://www.rainn.org/types-sexual-violence

http://www.kemh.health.wa.gov.au/services/sarc/what is.htm

http://www.wcsap.org/what-sexual-violence-sexual-abuse-and-sexual-assault