



**TRANSFORMING
HEALTH CARE TO
ADDRESS AND
PREVENT SEXUAL
VIOLENCE OF PEOPLE
WITH INTELLECTUAL
AND DEVELOPMENTAL
DISABILITIES**

Talk About Sexual Violence

▶ FINAL REPORT (2017–2023)

ABOUT THE PROJECT

The [Talk About Sexual Violence](#) project was generously supported by the WITH Foundation and implemented by The Board Resource Center (BRC) and The Arc's National Center on Criminal Justice and Disability® (NCCJD).

BRC provided project oversight, including contracting experts with intellectual and developmental disabilities, facilitating advisory groups, and drafting project deliverables, such as training videos and supplemental materials. NCCJD provided national outreach, co-creation, and final review of all project materials, as well as national dissemination of materials through digital outreach and social media.

This report and other project resources can be found at talkaboutsexualviolence.org.

PROJECT STAFF

Mark Starford, *The Board Resource Center*

Leigh Anne McKingsley, *The Arc's National Center on Criminal Justice and Disability*

Kecia Weller, *Self-Advocate Survivor, The Board Resource Center*

James R. Meadours, *Self-Advocate Survivor, Strategic Education Solutions*

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Chris Miller, Humboldt Community Access & Resource Center, CA

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FORWARD



James Meadours

As key advisors for this project, we bring a different perspective that no one else can. We are survivors with our own ideas for solutions, and we must be heard.



Kecia Weller

When we tell you we've been sexually assaulted, believe us! When we are not believed, we are dehumanized.



Chris Miller

Talking about sexual assault makes all people nervous, even a doctor. Too many victims remain in a sheltered world, afraid to share information because no one listens, or fearing not being believed and that victimization was their fault.



Pauline Bosma

Train doctors about persons with disabilities and about patients who are queer. Learn a little at a time. Be open.



OUR VISION

The Talk About Sexual Violence (TASV) project seeks to increase the capacity of health care providers and their delivery systems to effectively address sexual violence of patients with disabilities in the hope of reducing its occurrence, especially among people with intellectual and developmental disabilities (IDD).

Over the past seven years, TASV spurred honest and transparent conversations with health care providers, human service practitioners, disability rights advocates, abuse prevention colleagues, and their organizations, creating a spirit of collaboration that laid the foundation required to accomplish the project's goals.

While progress has been made, gains can and must continue. Increased health care provider awareness, access to and utilization of training materials, as well as intra and inter-organizational partnerships across disciplines, must persist in order to advance TASV's mission to educate health care providers about sexual violence of people with IDD.

Training and education that intentionally centers people with disabilities as teachers and leaders in this movement is one of the most important and effective strategies we can use to tackle this issue head-on and reduce the risk of sexual violence.

THE NEED

Sexual violence—sometimes referred to as sexual abuse or assault—against people with disabilities is an alarming public crisis. According to Leigh Ann Davis (2011), sexual violence is a crime of power and control involving any unwanted sexual contact. People with IDD and those who reside in residential services are at particularly higher risk. Violence among adults with intellectual disabilities may be compounded by multiple intersecting forms of discrimination experienced based on cognitive functioning and life circumstances. This vulnerability is associated with difficulties in reporting abuse or participating in justice systems, along with higher levels of dependence on paid or informal caregivers and living in supported accommodations.

The US Bureau of Justice Statistics found that one in five women is sexually assaulted. One in three adults with intellectual disability suffers sexual abuse. Furthermore, women and girls with IDD are four to 10 times more likely to face sexual assault, with nearly 90% experiencing sexual assault during their lifetime.

The rate of violent victimization against persons with disabilities is almost four times the rate for persons without disabilities. The national organization in 6 states nearly one in six men in the general population experience sexual assault and/or rape during their lifetime. The 2010 National Intimate Partner and Sexual Violence Survey found that men with disabilities were twice as likely as those without disabilities to experience sexual assault. The problem





is exacerbated when society leads men to believe that rape and sexual assault only happen to women, when in fact men—especially men with IDD—are also victimized at high rates.

Adult Protective Services (APS) providers are often first responders for survivors with disabilities. The National Adult Maltreatment Reporting System, 2020, reported that 41.9% of sexual assault cases involved someone with a cognitive disability. In 2021, the Department of Justice partnered with APS to create

training for law enforcement and encourage collaboration with APS. Unfortunately, these efforts centered on the aging population with no inclusion of victims with IDD.

With the intersections of disability and other identities, the risk of violence can be even higher. Studies have found that the LGBTQ+ community is significantly more likely to experience sexual violence than heterosexuals. Sexual violence impacts the IDD LGBTQ+ community, who endure even greater challenges disclosing victimization or reporting crimes. Transgender and non-binary individuals face staggering rates of sexual violence. Multiple studies indicate that LGBTQ+ individuals are at an increased risk of sexual violence compared with their heterosexual, cisgender counterparts.



Most significantly, learned reliance on caregivers and authority figures, as well as confusion about what sexual violence is, allows this trend to continue. Sexual violence is often not reported because individuals with IDD may not have or be aware of a safe person to turn to for help. To exacerbate these circumstances, only 12% of the general population is health care literate, meaning they don't have proficient skills to maintain health and use the US health care system successfully. Consequently, it is imperative that health care providers confront these realities and address sexual violence and its traumatic impact on their patients.

OUR GOALS

The overarching goals of the multi-year TASV project were to raise the alarm about the silent epidemic of sexual violence experienced by individuals with IDD, promote trauma-informed practices in health care, and compel action to prevent sexual trauma suffered in communities across the country.

Health care providers hold vital positions in the growing national movement to address sexual assault. Working with their patients and systems of care, health care providers can increase the likelihood that all patients are listened to, believed, supported, and better served. TASV acknowledges that health care providers are not expected to be the sole source of solutions, but they have a responsibility to listen to survivors, believe them, provide quality treatment, and direct them to local resources. This lays the groundwork for prevention.

Many health care providers are less informed about high rates of sexual violence among individuals with IDD and have little training in how to interact or communicate with patients with disabilities. In addition, patients with IDD are unlikely to talk about sexual violence on their own, often having limited health literacy and knowledge about what constitutes consent and sexual violence.

TASV provides resources and access to opportunities to increase professional capacities. The project concentrated on health care systems by creating sustainable tools and strategies for health care providers that enable functional, culturally competent communication with patients with disabilities who experience sexual assault. It also assists people with IDD and their allies to communicate more effectively about sexual violence and its prevention.





To reach greater numbers of health care providers, TASV partnered with specific professionals and self/peer survivors with IDD to sound the alarm about the urgency of addressing this epidemic. Dissemination of project tools to peers sought to build a cross-sectional prevention movement among the health care, self-advocacy, social, and disability service communities.

In addition to the medical profession, social workers also need training in sexual violence prevention of people with IDD. Abuse prevention is an area of considerable importance to the social work profession with its focus on social justice and human rights. Because social workers are employed in a broad range of human service organizations that support people with IDD, such as Adult Protective Services, they have a critical role in the development, implementation, and evaluation of sexual violence prevention strategies.

Self-advocacy groups are also essential in creating change by engaging persons with IDD to give voice to their lived experiences. Self-advocacy groups are often successful in creating sustainable policy and practice advances in the community. Accordingly, survivors with IDD must be engaged in this movement to create meaningful change. For example, the entire welfare system in Sweden was changed as a result of the work of self-advocacy groups. TASV strives to create new avenues for change with self-advocate survivors taking the lead.

PROJECT FINDINGS

TASV produced straightforward training videos and supplemental materials to guide health care providers in facilitating conversations with their patients about sexual assault. Training materials aimed to enhance the capacity and confidence of providers to address sexual assault and empower their patients with IDD to understand they can ask for help.

TASV recognized the need to reach out across human service professions and systems of care to prompt cross-disciplinary attention. During all project phases, the team continued to build cross-sectional associations among social service, health care, abuse prevention, advocacy, and disability communities in its call for prevention.

The formative approach used to meet project objectives underscored the emphasis on patient-centered, trauma-informed approaches to care. TASV was guided through its partnership with an advisory group of social service and medical professionals, victims' rights and APS providers, as well as self/peer advocate advisors with IDD who are survivors of sexual violence.



PHASE ONE focused on women with IDD who experience sexual violence. Digital tools were created to assist health care providers in employing patient-centered approaches when addressing sexual abuse and the use of effective communication strategies. Project materials, including a [Talk About Sexual Violence](#) webpage, were shared with health care providers through conference presentations, webinar series, and online dissemination. The initial project phase also sought to empower survivors of sexual assault by

producing short videos and guides to facilitate conversations about sexual violence with their health care providers. Focused learning sessions that included individuals with IDD, some of whom experienced sexual violence, sharpened attention to the requirement of delivering functional project tools. This, and additional guidance by a multidisciplinary team that included health care providers, informed all phases of TASV.

PHASE TWO turned its attention to specific challenges of men with IDD who experience sexual violence. Additional tools were created to assist health care providers in using supported decision-making with male patients to facilitate shared decision-making in treatment, referrals, and mandated reporting. These materials were circulated via presentations, webinars, and online. The TASV webpage was further developed to include presentations, topical recorded webinars, and additional digital tools.

PHASE THREE concentrated on building partnerships to advance the use of TASV materials by ensuring project tools were easily accessible online. While grounded in mandatory reporting requirements, TASV's activities and tools sought to cultivate a trauma-informed approach that included supported decision-making to broad audiences, as well as support advocacy systems within human services. The TASV team, through Kecia Weller's leadership, partnered with the National Peer Support Network to expand sexual violence awareness to self/peer advocacy organizations led by persons with IDD. The TASV team also worked within other statewide initiatives that feature self-advocate leaders, including the Arizona Sexual Violence & Disability Network and California's Silence = Violence Network.



CHALLENGES

Focus groups revealed institutional barriers that disconnected health care providers from patients with IDD, especially those who were survivors of sexual violence. Many discussed the lack of specific knowledge or experience in working with this patient population. This deficit, coupled with lack of guidelines and relevant tools, contributes to a health care system less equipped to respond when needed.

Specifically, focus group participants revealed challenges in the following systems or areas:

HEALTH CARE SYSTEMS

- Conversations about the topic are difficult and often avoided.
- There is a lack of training for health care providers on trauma informed approach.
- Patient load and time constraints prevent a patient centered approach during appointments.
- Billing for care, treatment, and referrals related to sexual assault may discourage the provision of adequate care.
- There is a lack of clarification about mandated reporting requirements.

HUMAN SERVICE SYSTEMS

- Many rape crisis centers remain inaccessible, and staff are not trained to work with survivors with IDD.
- Adult Protective Services (APS) is often the gateway to health care for survivors with disabilities, but service providers are not educated about accessibility and trauma-informed approaches.
- Victim service systems may not be familiar with communication strategies and trauma-informed approaches.
- Developmental disability services systems need education on sexual violence, how to provide referrals in the community, and how to work closely with APS and others. This issue is typically not prioritized.



ADVOCACY ORGANIZATIONS

- Self/peer advocacy organizations and their leadership reflect general avoidance of critically important topics like informed consent, sexual assault, and mandated reporting.
- There is a lack of training in supported decision-making, especially related to health care treatment and care.
- There is a scarcity of self-advocate survivors participating in the sexual assault prevention movement due to a lack of support to enable them to become leaders in this space.
- There is a lack of active participation from self-advocate survivors in research, presentations, training, and other outreach to the community.

COLLABORATION

- Few professional associations proactively reach outside of their disciplines to include sexual assault survivors with IDD (and their allies) to collaboratively address sexual violence.
- Few health care providers and delivery systems reach out to disability services to address the lack of coordination in care.

TRANSFORMATION IS POSSIBLE

How can we address an epidemic that is invisible? Sexual violence in all its forms continues to be a hidden epidemic in society. This is especially true for victims with IDD who often suffer in silence, with no one to help them make sense of their traumatic experience, and who may not know where to turn for help. Using a lens of transformative health justice (the intersection of health and justice systems to create a more just society for marginalized communities), we can reimagine a path forward.

Researchers and their institutions have yet to uncover the true extent of this crisis or to investigate ableism in health care and justice systems that leads to the discrimination of people with IDD. Future research must focus on ableism and how it impacts care for people with disabilities in the US, while including people with disabilities as co-investigators and co-authors on research articles. The term “the wisdom of the oppressed” summarizes the importance of involving those who are structurally discriminated against in the process of knowledge development. Otherwise, there is a risk that the structural oppression and injustices will be reproduced over time.

We must continue to advocate for research that focuses on the incidence of sexual violence in this population and how it negatively impacts care for millions of people with disabilities in the US. With this in mind, the following recommendations can also lay the groundwork for the beginning of a transformation that people with disabilities and allies are seeking.



HEALTH CARE SYSTEMS

- Increase inclusive quality care.
- Mandate training on sexual assault of persons with IDD and care approaches through online learning tools, such as TASV resources and other mechanisms.
- Provide necessary accommodations for patients with disabilities (e.g., functional language communication, multi-media charts and formats, and accessible rooms).
- Provide comprehensive training on sexual violence and patient-centered care for health care providers, including medical students, through continuing education opportunities.
- Identify and support leaders in health care who can raise awareness, advocate for training, promote best practices, and publish articles in relevant medical journals.
- Incentivize health systems to join national disability coalitions and regional networks.

ADVOCACY AND COLLABORATION

- Create a process for ongoing collaboration between Adult Protective Services, law enforcement, and criminal justice advocates to sustain the sexual assault prevention movement and provide adequate funding to ensure its success.
- Create a process for ongoing collaboration with national networks, advocates, and multi-disciplinary teams to extend the sexual assault prevention movement and provide adequate funding to ensure its success.
- Incorporate principles of patient advocacy that include treating patients with IDD with respect and involving them in decisions about their health.
- Assure that person-centered care is a health care right and that it is the centerpiece of treatment and support.

A CALL TO ACTION

The final call to action comes from survivor self-advocates who are devoting much of their professional and personal lives to addressing the hidden epidemic of sexual violence against people with IDD. Without their lived experience, rich insight, and honest contributions to this topic, there would be little hope for change. We must listen carefully to valuable nuggets of truth that will ignite the transformation.

James and Kecia offer the following call to action to health care professionals:



James Meadours

- Ensure survivors with IDD are co-trainers and advisors in this work.
- Expand the doctor's oath of "first, do no harm" to include awareness of victims' experiences of sexual assault.
- Talk to self-advocacy groups and disability service providers about how to talk to doctors about sexual assault.
- Start talking about the impact of sexual assault within your own health care clinics and offices.
- Use a patient-centered approach with survivors.



Kecia Weller

- As mandated reporters, please report!
- Learn about the signs of possible sexual assault; believe us.
- Work with agencies that have abuse prevention campaigns.
- Develop inclusive train-the-trainer models.
- Be aware of implicit bias against people with disabilities.
- Advocate for sex education of youth and students with IDD.
- Learn about ableism and the impact it has on patients with IDD.

Finally, we call on every person reading this report to commit to listening, believing, supporting, and offering hope to any sexual violence survivor you meet. You may be their only hope.

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FOR MORE INFORMATION

The Arc's National Center on Criminal Justice and Disability (NCCJD) serves as a bridge between the disability and criminal justice communities while advocating at the intersection of criminal justice reform and the advancement of disability rights. Visit NCCJD online: thearc.org/NCCJD

Talk About Sexual Violence is a project of NCCJD that educates healthcare professionals about how to talk to their patients with intellectual and developmental disabilities about sexual violence. Find project description and resources at: talkaboutsexualviolence.org

Take the pledge to Talk About Sexual Violence: thearc.org/pledge-to-stop-sexual-abuse-disability/