FINAL REPORT

Talk About Sexual Violence: Male Survivors

September 2019

"We are told to be strong, not to cry or share feelings.

These ideas are communicated from an early age; the expectations of manhood are very high and never include opening up about any type of abuse, especially sexual assault and violence perpetrated against them, as an adult or child. Many of us do not believe there will be any consequences even if we do tell. This is a deep reaching issue that we must deal with to have a healthy, inclusive, and safer society. Every sexual assault survivor needs to know they matter, are respected, and can be safe."

- Chris Miller, Disability Rights Advocate



About Talk About Sexual Violence

Phase Two of *Talk About Sexual Violence*, which focuses on male survivors with intellectual and developmental disabilities (I/DD), was generously funded by the WITH Foundation and carried out by the Board Resource Center (BRC) and The Arc's National Center on Criminal Justice and Disability® (NCCJD®). The Board Resource Center facilitated advisory group meetings and individual interviews and produced project training tools and supplemental materials. The Arc provided subject matter expertise for all project materials and designed, disseminated, and hosts these materials on their website. This report and project resources can be found at: talkaboutsexualviolence.org

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Forward: Thoughts From Kecia Weller and James Meadours





People with intellectual/developmental disabilities (I/DD) face many challenges when it comes to sexual violence:

- Sex and sexual violence are often taboo subjects most people want to avoid. People with I/DD are overprotected, can't grow to express themselves, be independent, and share painful information.
- Professionals may take on the role of "parent," and NOT act as our true ally.
- Too many victims remain in a sheltered world, afraid to share information, keeping feelings in because no one listens, or fearing not being believed and that victimization was their fault.

People can overcome trauma and take charge of their lives:

- We need people who believe us and let us be independent and grow.
- We need to be in the community, not be put in a "dome" that is too protective.
- Talking about sexual assault makes all people nervous, even doctors.
- Health care providers are mandated to call Adult Protective Services, let them do this important job.

The value of the Talk About Sexual Violence Project:

- Sexual assault can and does happen to anyone disability or not.
- All of us can learn how to start conversations with victims, including health care providers.
- Remind health care providers that they are mandated reporters.
- Know there are people who want to help.

If we can do it, other people with disabilities can do it too! It's hard. At times it doesn't feel like the confusion will end, but it does – when you share what happened with people you can trust.



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A Personal Story

JAMES MEADOURS

SHINING THE LIGHT ON A SILENT EPIDEMIC

I am James Meadours and I live in San Antonio, Texas. I am a sexual violence survivor and person with an intellectual/developmental disability. Also, I am a national peer advocate for victims with disabilities and speak to many groups about stopping violence against people with developmental disabilities. We experience sexual assault and violence at a rate that is seven times higher than the general population. And, it happens over and over to us.

My story is not unique. I never thought lightning could strike twice, or over and over in the same place. It did in my life. I was sexually assaulted four times. The most recent time was when I was looking for a church that welcomed all people.

A friend told me about her church. And I went with her. I met a member who was deaf. He wanted to teach me sign language. I thought we could be friends. One time he asked if I was gay. I told him I was not. We got together at my apartment the day before church where I lived alone. He began to be sexual with me. He knew I was not gay. But he touched me. I told him I was not interested. I shook my head "NO". I backed away and used sign language to say NO. He signed YES. He kissed me and forced me to take my clothes off. I resisted. He made me have sex. He did not leave until church the next day.

At church I didn't tell anyone. I felt ashamed and afraid. I believed I would be hurt. I reached out to the Pastor. Nothing was done. I was alone. I was frustrated and told a friend. He called 211 for me. He made a report with my permission. I went to the hospital to make sure I was OK. The Sexual Assault Nurse Examiner was very understanding. And I made my report to the police. An officer came to my home and took evidence. He was kind. I pressed charges and went to court. The abuser went to jail. Later, I needed help, so I went to the rape crisis center. They did not know how to support me, [they] had never worked with a man with developmental disabilities. But they tried.

In the end, no one taught me recovery steps. I learned on my own with people supporting me. Now, I want to tell my story and help others. I am a passionate advocate for victims with disabilities. Last year I was in a national public service announcement. It was made by the organization called 1in6. Six men who were raped, including me, told our stories. It was the first time they included a man with disabilities in their videos or materials.

Many of us are afraid to report. We think people would not believe us. So we don't report, and the cycle continues. If we work side by side, we CAN improve many people's lives.



Background

After the release of videos and other materials created for the *Talk About Sexual Violence* project in 2017—which focused on women with intellectual/developmental disabilities (I/DD) who experience sexual violence—the project team was approached by males with I/DD who are survivors of sexual assault about crimes perpetrated against them. People with I/DD report that many health care providers are uneducated about how to interact with patients with disabilities and don't know about their high risk of sexual violence. The problem is exacerbated when society leads men to believe that rape and sexual assault only happen to women, when in fact men, and especially men with I/DD, are victimized at alarmingly high rates. Sexual violence also impacts the I/DD LGBTQ community, who face even greater risk and challenges disclosing or reporting victimization.

For this reason, in 2018 *Talk About Sexual Violence* turned its attention to specific challenges men with disabilities experience. According to the national organization 1in6, about 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 violence, other than rape. Researchers also found the prevalence of lifetime sexual victimization is 14 percent among men with disabilities compared to four percent among men without.

When looking at the intersections of disability and other identities, risk of violence can be even higher. For example, it's important to keep in mind that transgender and non-binary individuals face staggering rates of sexual violence. Preliminary research points to nearly half experiencing sexual assault at some point in their lifetime. In communities of color, numbers are even higher.

For these compelling reasons, it is critical that health care professionals and their patients talk openly about sexual violence prevention. *Talk About Sexual Violence* provides tools that help create a safe place to have these conversations. With increased awareness of the prevalence of sexual violence, along with the use of effective communication strategies, health care professionals can confidently help patients feel more comfortable when discussing sexual violence, leading to increased reporting of these crimes.



Purpose

IMPACT ON HEALTH CARE DELIVERY

Due to the nature of their professions, health care providers have unique opportunities to prevent or stop sexual violence. However, many have not had experience talking about sexual victimization with men with I/DD. Most men with disabilities are unlikely to raise the topic of sexual violence on their own, and often have limited health literacy or knowledge about what constitutes sexual crimes or victimization.

Health literacy is defined as "... the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions." Recent surveys reveal that only 12 percent of adults in the U.S. are proficient in their ability to maintain health, prevent disease, and use their health care system. It is imperative that health care providers take measures to address this dilemma head on. When tackling these critical needs, it is vital that they utilize training and tools that assist with communicating effectively, so that they can provide patients with I/DD emotionally safe environments where they can talk candidly about their experiences.

GOALS AND OBJECTIVES

Phase Two of *Talk About Sexual Violence* assists health care providers, men with I/DD, and their allies to communicate about sexual violence. To accomplish this, the project team of The Board Resource Center and The Arc's NCCJD developed straightforward, accessible training tools and supplemental materials to guide professionals in conversations with patients about sexual violence. Deliverables and outreach activities included:

1. Three brief training videos

- "How to Have the Conversation"
- "James Meets with his Doctor"
- "Peer Advocates Talk About Sexual Violence"

2. Supplemental materials

- Training Guide & PowerPoint slides
- Communication tools
- Online resource list of useful organizations

3. Outreach

- Facilitated workshops at state and national health care and disability conferences
- Interviewed health care providers and social workers
- Peer advisors presented at state California Adult Protective Services (APS) event and self-advocacy conference
- Presented project tools to California disability service and advocacy groups



Project Methods

TALK ABOUT SEXUAL VIOLENCE: PHASE ONE (2017)

The first phase of *Talk About Sexual Violence* focused on building health care provider competencies when serving women with I/DD who may have experienced sexual violence. It was guided by an advisory group of social service and medical professionals, including a primary care physician, disability service medical directors, self- and peer advocates with I/DD, victims' rights and adult protective service providers, and a California developmental disabilities services training officer. The group met to focus on project objectives specific to development of training videos and supplemental materials for the target audience of primary care providers who see women with I/DD in their everyday practice. After a review of project tools in draft and final form, advisors provided recommendations for continued training, advocacy, and public awareness.

TALK ABOUT SEXUAL VIOLENCE: PHASE TWO (2019)

Since the completion of Phase One, there has been increased interest in examining the prevalence of sexual assault and violence perpetrated against men and boys. With cultural shifts, broader media attention, and men coming forward with their personal experiences, it was imperative to address the hidden population of men with I/DD who have been victimized. In order for more men to come forward, health care providers need to be knowledgeable about how to communicate, provide time during patient appointments, and understand their mandated reporting responsibility. The project team, with continued funding from the WITH Foundation, sought to address this need by developing easy-to-use tools for health care professionals and their staff.

Recognizing the significance of consumer engagement in successful models of care delivery, Phase Two ensured that perspectives of end-users guided the work, and included health care professionals, men with I/DD, and leaders of support service organizations and advocacy groups. This formative approach leads to outcomes shaped by needs and preferences of target audiences and wider utilization of tools. BRC's work also emphasizes a "plain language" practice that promotes availability of functional information to support informed decision making and action by all stakeholders.

The advisory group met twice, with BRC facilitating additional individual conversations with key health care, social service, and survivor advisors. There were also numerous meetings with primary health care providers to determine their understanding of the issue and reporting requirements. The group meetings were designed as interactive sessions to provide advice on content and plain language needs for project videos and supplemental materials.



Project Outcomes

Talk About Sexual Violence was designed by The Board Resource Center and The Arc's National Center on Criminal Justice and Disability. Their lengthy experience with development of training and tools for broad audiences demonstrated that easier access to content and use of multi-media leads to greater utilization by end users. Mindful of this course, Phases One and Two of the project focused on providing professionals straightforward guidance on caring for women and men with I/DD when addressing sexual violence. It equips health care providers with basic tools to facilitate conversations, support patients, and report crimes.

During and after production of *Talk About Sexual Violence* Phase One materials in 2017, project team members and several advisors established partnerships aimed at sexual violence prevention and better coordination among health care and support service organizations. Advocacy organizations approached the team and requested opportunities to learn more about the frequency of sexual assault against persons with I/DD. Areas of interest included survivor stories and recommendations regarding improved access to victim services. Notably, team members observed a marked interest on the part of service and advocacy groups to invite women with disabilities to join their outreach partnerships. Phase Two of the project anticipates similar requests after completion and dissemination of project materials.

After Phase One was completed, the project team was successful in expanding discussions in advocacy arenas, including in service provider communities.

PHASE ONE OUTREACH AND DISSEMINATION

Events and Conferences 2017 - 2018

- Supported Life Conference, Sacramento, California (Abuse Awareness track)
- California Department of Social Services/Adult Protective Services (Sexual Assault Awareness Month event)
- Vera Institute (Participation: Ending Violence Against People with Disabilities Coalition)
- Silence = Violence Network (Co-founding California Dependent Adult/Elder Justice Coalition)

Media and Blog Postings 2017 - 2018

- Blog posting by the National Sexual Violence Resource Center (NSVRC) written by James Meadours and Leigh Ann Davis for Sexual Assault Awareness Month
- Blog posting by Kecia Weller "My #MeToo Story" on The Arc's blog
- Blog postings on The Arc's national website
- Blog on 1in6 website written by James Meadours and Leigh Ann Davis
- Feature of James Meadours in 1in6 PSA for Sexual Assault Awareness Month



 Two features/interviews by James Meadours on NPR "Abused and Betrayed" Series

PHASE TWO DELIVERABLES

Three short videos: "How to Have the Conversation," "James Meets with his Doctor," and "Peer Advocates *Talk about Sexual Violence*" are available in English with English and Spanish transcripts. Project training materials and resources that accompany the videos are also available in Spanish and English and accessible on The Arc's website: www.talkaboutsexualviolence.org.

Project materials include:

1. Training

- PowerPoint slides highlighting key points from the videos
- Training Guide for health care providers
- Conversation Guide of tips for advocacy groups and allies to facilitate conversations
- Infographics of key data that reflect the sexual assault epidemic

2. Communication Tools

- Alternative communication charts (body, words, expressions)
- Referral card to support agency/organizations

3. Resources

- Aggregated list of resources, including other organizations and data
 - Community support, victims' rights organizations
 - Research (e.g., crimes against people with disabilities, gender non-conforming individuals)

Dissemination

Talk About Sexual Violence materials are housed on The Arc's website in the criminal justice section. All tools and videos are directed at health care provider organizations, disability advocacy groups, victim service providers, and California developmental service regional centers. In addition, web links to hotlines and support for crime victims, as well as resources related to professional reporting responsibilities, patient-centered communication, and sexual violence prevention are provided. The announcement of the project utilizes The Arc's extensive online outreach capabilities through email, blogs, and social media, as well as BRC's California network. Utilization will continue to be measured by number of users who access project resources online.



Events and Conferences 2018 - 2019

- Developmental Disabilities Nurses Association Conference (Presentation: Sexual Assault Prevention)
- California I/DD Advocacy conference (Keynote address: Sexual Abuse Prevention)
- Silence = Violence Network (Presentation: Human Trafficking of People with I/DD)
- National Conference on Sexual Health (Panel presentation: Sexual Violence Prevention)
- Vera Institute (Member, Ending Violence Against People with Disabilities Coalition)
- California Supported Life Conference (Project presentation: Sexual Assault Epidemic)
- NAPSA (Convening 1st National Conference to establish plan to reduce sexual violence)

Media and Blog Postings 2018 – 2019

- MS magazine article written by Kecia Weller
- Blog posting by National Sexual Violence Resource Center (NSVRC) written by James Meadours and Leigh Ann Davis for Sexual Assault Awareness Month
- Blog posting by The SAFE Alliance written by James Meadours
- Four blog postings by The Arc's national office on sexual assault epidemic against men with I/DD



Recommendations

FROM ADVISORS AND SELF-ADVOCATES

Talk about Sexual Violence advisory groups and self-advocates offered recommendations for expanded sexual violence prevention and victim support. Given their strong commitment and the ongoing work of BRC and The Arc's NCCJD, these are included for future consideration.

1. Increase mandated reporting of sexual violence by health care professionals

- Increase training to better recognize signs of sexual abuse, assault, and violence
- Increase training of mandated reporter responsibilities and legal limitations of liability
- Increase awareness of the role of Adult Protective Services
- Increase understanding of I/DD, gender non-conforming patients

2. Increase victim understanding of sexual violence

- Use short videos/multimedia materials in facilitated group discussions
- Provide agency case workers with materials to facilitate conversations
- Create a one-page handout and video about sexual violence and victim resources
- Assist persons at risk to develop safety plans and include the topic in special education curricula
- Include people with I/DD in law enforcement training

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

- Conduct presentations at professional health care conferences
- Conduct presentations at sexual health conferences
- Increase outreach to small community health care providers
- Target health care providers to conduct in-house training using project tools
- Conduct training events at California regional centers utilizing staff and peer advocates
- Broaden reach by working with anti-violence campaigns and campaigns promoting sexual health
- Ensure adult protective service staff and social workers are educated about sexual violence against persons with I/DD



Acknowledgments

The WITH Foundation strives to promote the establishment of comprehensive health care for adults with intellectual/developmental disabilities. WITH funds programs that improve health care delivery to address the fundamental and unique needs of individuals with various health care conditions.

withfoundation.org

The Arc's National Center on Criminal Justice and Disability® is funded, in part, by the U.S. Department of Justice. It is one of the only national resources that looks equally at both victim and suspect/defendant issues involving people with intellectual and developmental disabilities. NCCJD is the national focal point for collection and dissemination of resources and serves as a bridge between justice and disability professionals. It promotes safety, fairness, and justice for all people with I/DD as suspects, defendants, victims or witnesses. thearc.org/criminal-justice

The Board Resource Center works from its founding principle of Making Complex Ideas Simple to meet needs of individuals and organizations that foster leadership, self-determination, and community inclusion. Focus areas include person-centered strategies and multi-media plain language products with broad usability to increase informed decision-making, civic engagement, and advocacy.

brcenter.org

Project Advisors provided time and insight into the ongoing silent epidemic of sexual violence perpetrated against people with I/DD. Advisors met in small groups and provided individual interviews. The project team is grateful to the professionals that provided insight and honest responses about what is needed in care communities to increase reporting.

PEOPLE WITH DISABILITIES

James Meadours, National advocate and speaker, San Antonio, TX

Kecia Weller, National advocate and speaker, Los Angeles, CA

Michael Emory, Self-Advocate Survivor, Sacramento, CA

David Lopez, Client Advocate, Alta California Regional Center, Sacramento, CA

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End Notes: Looking to the Future

Over the last three years, *Talk About Sexual Violence* has grown into a catalyst for a more vibrant and effective movement. There have been many relationships and discoveries made in the past three years during both project phases that led to significant outcomes, especially with crafting key messages about sexual violence prevention and people with I/DD for health care professionals. Project consultants, who are survivors with I/DD, found new national platforms from which to share these messages, and the disability and health care communities are beginning to take notice. While progress has been made, there is still much work to do. *Talk About Sexual Violence* is more than a project—it has become a campaign of survivors with I/DD and their allies working together to start the much-needed conversation, erase stigma, and find solutions.

As we look to the future, one thing is for certain: this movement cannot be successful without people with disabilities taking the lead. There is much untapped knowledge, experience, and passion of survivors and people with disabilities. Such strengths must be strategically utilized to make the impact we know is needed. *Talk About Sexual Violence* seeks to engage more and more people with I/DD to be part of the solution, one survivor at a time.