

Maine Developmental Disabilities Council

January 9, 2024

Testimony in **Support** LD 254 An Act to Update the Sex Education and Consent Curriculum.

Senator Rafferty, Representative Brennan and the distinguished members of the Committee on Education and Cultural Affairs:

My name is Nancy Cronin, and I am the Executive Director of the Maine Developmental Disabilities (DD) Council.¹ I am here to testify in Support of this bill the part that would expand sexual health education to underserved populations. Children and youth with Intellectual / Developmental Disabilities (I/DD) need sex education and often are excluded from that part of the curriculum. The reasons for the exclusion are many and could include parents who think their child isn't ready for the topic, the thought that the individual will never have sex or be sexual, or there isn't enough time in the day so a topic like this is pushed aside in light of special education or other related services.

I am here today to say excluding students with I/DD is a very, very big mistake. Did you know that people with I/DD are not only much more likely to experience sexual assault, but they are also likely to experience abuse repeatedly.² Decades of research suggest an ongoing crisis; there is an alarmingly high rate of physical abuse, neglect, and sexual victimization among those with I/DD.^{3,4,5} Researchers have found that more than 80% of people with I/DD will

¹ Councils on Developmental Disabilities were created through the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) in 1970. There has been Maine's DD Council has been advocating with and for individuals with developmental disabilities for over 50 years. The DD Council is a federally funded, independent organization with members from across the state, including persons with disabilities, family members, and representatives of public and private agencies which provide services and/or funding for services for individuals with developmental disabilities. As required in federal law, we are involved in advocacy, capacity building and systemic change activities, with the goal that individuals with developmental and other disabilities of all ages are fully included, integrated, and involved in their communities and the decisions impacting their lives.

² Shapiro, Joseph (2018) The Sexual Assault Epidemic No One Talks About. Department of Justice Data Accessed on 10/14/2022 <https://www.npr.org/2018/01/08/570224090/the-sexual-assault-epidemic-no-one-talks-about>

³ Sobsey, D., D. Wells, R. Lucardie, and S. Mansell. 1995. Violence and Disability: An Annotated Bibliography. Baltimore, MD. Brookes Publishing.

⁴ Baladerian, N. Coleman, T., & Stream, J. (2013). A report on the 2012 national survey on abuse of people with disabilities: Victims and their families speak out. Spectrum Institute Disability and Abuse Project

⁵ Daigle, L. (2017). Victimology: The essentials. Sage Publications, New York, New York.

experience some form of sexual abuse at some time in their lives. ⁶ One key contributor to the high rates of abuse are that people with I/DD are never taught about sexual health. Another key contributor is the stigma that people with I/DD having sex is taboo. This puts people at risk of unhealthy relations should they one day wish to experience greater intimacy. But this also puts people at real risk because when abuse does happen, people without disabilities have trouble acknowledging that having sex with a person who has I/DD is real. Because of that stigma abuse can occur for years and people with I/DD are left without the very words to describe what is happening.

Part of preventing sexual abuse is allowing people with I/DD to learn about sexual health. Understand the names of body parts and the concept of consent. This is why I am here.

In 2022, a student in Maine who has autism was sexually abused in a school by an adult. MDCC received a call from a local psychological center asking if we knew of any evidence-based therapies to help individuals with I/DD who have been abused or witnessed abuse. At the time there was very little available nationwide. We funded a community of praxis with experts from around the country. Their recommendations on how to provide care is attached.

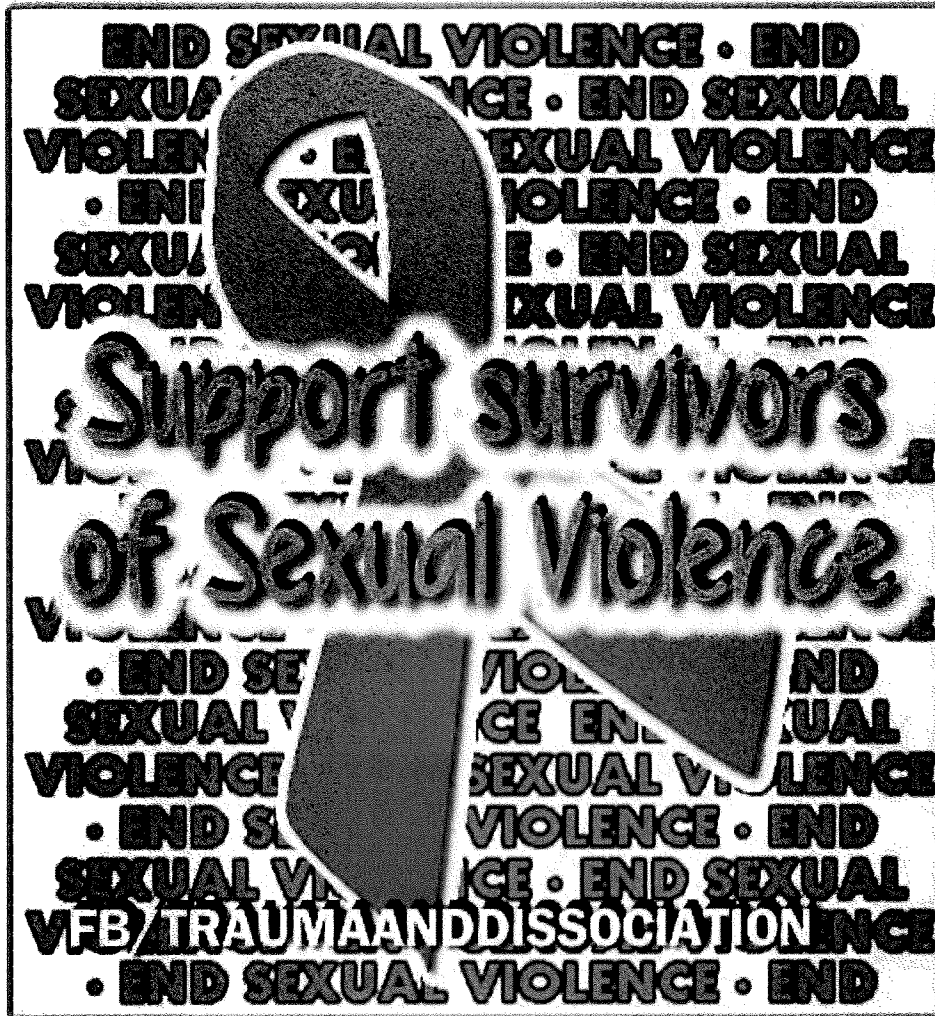
I am happy to say that in 2023 over 50 Maine mental health professionals were trained in Trauma Focused CBT to be able to respond and provide care for sex abuse victims who have I/DD. Our mental healthcare team stands ready for when it does happen. But I am here today hoping to prevent it happening at all.

Whatever this bill is, I hope that it will make a statement that sexual health education should not be viewed as just another “special” class. Every effort should be made to bridge this sometimes-uncomfortable topic and include students with I/DD to receive the information with their peers. Not only will this provide critical information to students with I/DD but will reduce stigma and maybe stop abuse from happening to someone with I/DD.

Thank you for this opportunity to provide input and I am available for any questions.

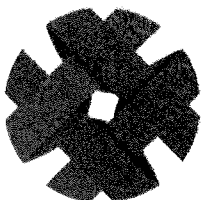
A handwritten signature in black ink, appearing to be 'J. Coleman'.

⁶ Baladerian, N. Coleman, T., & Stream, J. (2013). A report on the 2012 national survey on abuse of people with disabilities: Victims and their families speak out. Spectrum Institute Disability and Abuse Project



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Resources for health providers responding to sexual assault of people with intellectual disabilities



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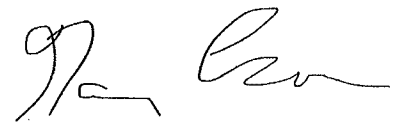
Maryann Harakall
CSHN Representative

To Whom it May Concern:

People with Developmental Disabilities are often at an increased risk of experiencing or witnessing sexual abuse. It is an unfortunate truth that, currently people with Developmental Disabilities are often not seen as sexual beings by the general population and that bias puts people with Developmental Disabilities at greater risk of abuse and not being able to access help from being victims or witnessing sexual abuse. Unfortunately, until sexual abuse and trauma is eliminated, professionals will be needed to provide care for the victims.

A few years ago, it came to the Maine Developmental Disabilities Council attention that health and mental health care professionals needed additional resources to be able to care for individuals with Developmental Disabilities who experience or witness sexual abuse and trauma. In response we funded a Community of Praxis full of experts to develop this starting place for those professionals. It is our great hope that this resource guide will prove useful and that people with Developmental Disabilities who need help will be able to get that help close to their home in their local communities.

Thank you for taking the time to review this resource.



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This report documents the work of the Community of Praxis, and we hope it will serve as an initial resource for providers/clinicians supporting individuals with Intellectual and Developmental Disabilities (I/DD) who have experienced or witnessed sexual trauma, and as an early road map for future research, policy, and practice agendas. This document reflects the general consensus among the participants as key strategies for clinicians, priority resources for information, and ideas for future system change activity.

This project was supported, in part by grant number 2001MESD-02, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy.

Introduction

People with intellectual and developmental disabilities (I/DD) are not only much more likely to experience sexual assault, but they are also likely to experience abuse repeatedly.¹ Yet access to medical and mental health professionals willing or able to assist the victim in healing is minimal.

Decades of research suggest an ongoing crisis; there is an alarmingly high rate of physical abuse, neglect, and sexual victimization among those with I/DD.^{2,3,4} Researchers have found that more than 80% of people with I/DD will experience some form of sexual abuse at some time in their lives.⁵ There has been a great deal of research and resources committed to develop programs aimed at teaching individuals with I/DD about sexuality but less to ensure that professionals feel competent in providing care of victim. Prevention efforts are a critical piece but are only part of the equation. Until sexual abuse of individuals with I/DD can be eliminated, victims need care.

For decades, professionals have been aware that individuals with I/DD experience shockingly high rates of sexual assault and abuse. Nevertheless, accessing comprehensive medical and mental health treatment can be difficult for those who have disabilities and the issue only compounds if the individual has I/DD and communication challenges. However, like everyone else, individuals with I/DD may desperately need help from medical and mental health professionals

Until sexual abuse of individuals with I/DD is eliminated, victims need care.

Maine Developmental Disabilities Council has noted that the issue is twofold: First, professional trauma therapists and other practitioners express concern that they do not have the necessary skill to work with clients who have I/DD and potentially turn them away because they feel as though they won't be effective; Second, therapists fluent in working with clients with I/DD feel that they don't have the skill to treat trauma. This leaves the individual with I/DD without many places to find help in the medical and mental health fields. MDDC has received calls from healthcare providers looking to access referral and resources to address the mental health of victims of all ages who also have I/DD as well as providers looking for resources about how to address the vicarious trauma of witnesses who have, or don't have, I/DD. *MDDC realized that there wasn't an easy answer and therefore conceived the Community of Praxis*

¹ Shapiro, Joseph (2018) The Sexual Assault Epidemic No One Talks About. Department of Justice Data Accessed on 10/14/2022 <https://www.npr.org/2018/01/08/570224090/the-sexual-assault-epidemic-no-one-talks-about>

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⁴ Daigle, L. (2017). Victimology: The essentials. Sage Publications, New York, New York.

⁵ Baladerian, N. Coleman, T., & Stream, J. (2013). A report on the 2012 national survey on abuse of people with disabilities: Victims and their families speak out. Spectrum Institute Disability and Abuse Project

Maine Developmental Disabilities Council

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as a way to increase clinical capacity and professional ability to support people with I/DD who have experienced sexual abuse.

Process: Community of Praxis

During the summer of 2022, MDDC gathered seven clinicians practicing from Maine to Philadelphia and Washington, D.C. to form the Community of Praxis. Participants included practitioners with clinical expertise treating diverse individuals with I/DD, including children and adults with limited communication skills, as well as practitioners with clinical expertise in trauma informed care and treating individuals without I/DD who have experienced sexual abuse.

The Community of Praxis brought these experts together to share their diverse knowledge, create a resource compendium of existing best or emerging practice, and to develop recommendations to improve the care of individuals with developmental disabilities who have experienced or witnessed sexual assault.

In addition, an Advisory Committee to the Community of Praxis was developed. The Advisory Committee was composed of representatives from the statewide self-advocacy organization for people with I/DD, parents, families, caregivers of individuals with DD, and the statewide advocacy organization charged with the task to work towards the end sexual violence by advocacy, victim response, and prevention programs. The Committee reviewed agendas and findings then provided feedback on key questions from the perspective of individuals with lived experience.

While the Community of Praxis focused on current practice for treatment of trauma and sexual abuse/assault experienced by people with I/DD, they recognized the sometimes-insurmountable barriers to treatment could not be addressed. These included structural barriers such as the availability, affordability, accessibility of care, cultural barriers, individual barriers (fear), and the way stigma profoundly impacts everyone and all aspects of this difficult topic. The Community of Praxis acknowledged that these barriers were outside the scope of the project and that they could not solve all problems or issues. They decided to focus on increasing professionals' capacity to provide treatment of victims and create a pathway that others could follow towards the goal of ensuring people with I/DD who were victimized received needed care.

Key Strategies

After multiple meetings each, the Community of Praxis and the Advisory Committee developed the following strategies to address professional's capacity to provide treatment to people with I/DD who are victims of sexual abuse or witnesses to sexual abuse. The Community of Praxis and the Advisory Committee recognize that this is only a start and more needs to be accomplished to provide treatment to those in need.

Clinical Strategies

Overall message to clinicians

- **Clinicians can treat individuals with I/DD, even if it isn't their specialty. They don't have to be an expert!** This is especially important for clinicians who already have a relationship with person with I/DD affected by trauma.
- Take the time to establish a therapeutic relationship. Take the time needed to work with the person with I/DD. The path forward will be a very *individualized* process.
- **Trauma-focused cognitive behavioral therapy (TF CBT) can be adapted to treat people with I/DD by:**
 - Slowing down,
 - Using visuals,
 - Using repetition in communication,
 - Shorten the sessions,
 - Using play,
 - Taking the time that's needed (perhaps 24 sessions not 12) and more.
- Become familiar of evidence-based resources, toolkits, webinars, books. The Clinician can begin using the references cited in this resource. That said, research is emerging, keep an eye out for new information.
- Adapt current clinician skills and practices to work with the individual with I/DD seeking treatment for trauma.
- Consult with other clinicians to brainstorm the best path forward while maintaining the healing therapeutic relationship.

"Don't give up on a relationship just because you don't think you know all the next steps in treating them."

Foundation

Establish Safety

- **Assess safety!** Ask is the individual *safe now, for example is the individual with I/DD still in contact with the perpetrator?*
- Ensure the person is and feels safe so they can be comfortable talking. Clearly establish your role.

- Get a clear idea about *who* the individual with I/DD trusts. Individuals with I/DD often have multiple caregivers. Determine how many different people come and go from the life of the individual with I/DD. Examine how that might affect the individual's level of trust and sense of safety.

*A skilled clinician who takes the time to adapt practices
is much better than a person getting no support or
treatment.*

- Don't assume that the person who accompanies the individual with I/DD knows the person well. Ideally, the initial conversation should be with the client only so they can share who they would feel comfortable also being in the room. Try to ensure that someone who is part of their lived experience (maybe not clinical, rather find a companion/friend) can accompany them. Let the individual with I/DD know that they can have "safe" people with them during conversation/counseling. If appropriate involve the person's family. Consider using family structured interventions.
- Ensure that the practical issues about the case/event have been completed. For example, reporting to/from various entities like the police, guardian, adult protection, and incident reports.
- Be aware that individuals with I/DD can be very afraid of getting "in trouble" themselves or that someone will "be mad" at them. This can affect how much of their story they feel comfortable sharing.
- Ensure that the individual with I/DD and their supporters, including the guardian as appropriate, understand confidentiality in the therapeutic relationship.
- Recognize other providers/roles who may be involved such as the emergency department, police/law enforcement, primary care provider, pediatrician, sexual assault support provider, community support agency, case manager.
- Conduct a thorough intake. In order to determine where the clinician needs to start they need to understand the individual's background. What is/are their:
 - Diagnosis,
 - Strengths,
 - Social History,
 - Mental Health History (Including other treating providers),
 - Education/Academic Skills
 - Physical History
 - Existence of previous trauma history, common to this population, including:
 - Restraint and seclusion,
 - Frequent hospitalizations,
 - Early removal from home into residential living.
 - Relevant history leading to referral. This will vary by clinician's role.
 - Desired outcome as a result of treatment.

Communication: “Talk to Me” Ensure that all clinician communication and treatment is directed to the individual, not the caregiver. (This sentiment was strongly reinforced by the Advisory Committee who represented the lived experience of I/DD.)

- Use basic counseling methods such as smiling, comfortably sitting back, and engaging using conversational tones.
- Ask the person what would make the space more comfortable, and how they want to be supported.
- Be aware that the clinician will likely not always, and may never, get the whole story right away.
- Make no assumptions about what the person with I/DD knows or doesn't know.
- Know who the individual's support people are. Be aware of who the people are that is telling the story. Sometimes the support person who is bringing the individual with I/DD to the appointment may not know them well or may have heard the story from a different caregiver. This creates a risk of “telephone” syndrome in the retelling of the story and may affect the level of accuracy of information. Be aware of potential bias by the support person presenting behavior.
- Make sure it's understood that “this is (the person's) story.” People with I/DD often have less power in their lives than people without disabilities. Make sure that the person with I/DD has the opportunity to have control over their story. Establish clearly that it is up to the person to decide how, and, when to tell their story. Make sure it is clear to caregivers and the individual that they can have privacy about the story if they so choose. This boundary, in and of itself, may be healing to the individual with I/DD.
- As the individual with I/DD moves through their story support them to understand what happened. Be prepared to help the individual with I/DD access and use words (physical and biological) so they can tell and understand their story.
- Normalize the conversation about sex/sex education (try to remove taboo). Be aware of whether the person has the knowledge and vocabulary to fill in the gaps in their knowledge. Feel free to use tools such as visuals and dolls to assist this process.
- Be aware and build awareness that individuals with I/DD, like everyone else, have multiple identities. Be respectful of cultural issues and intersectionality in clinical responses for example consider intergenerational trauma, gender, and historical/institutional racism.

Therapeutic Tips

- Trauma-Focused Cognitive Behavioral Therapy (TF CBT) often works well for the early period of therapy when an individual has first disclosed the trauma and providing next steps. TF-CBT can be good at building shared understanding between the individual with I/DD and others in their life about what has happened.
- Include clarity about clinical goals and strategies in plain language.
- Assist the individual in building their vocabulary about what happened.
- Consider using the “social stories” model to teach coping skills for those with I/DD experiencing anxiety & trauma. Modify existing evidence-based techniques for treating anxiety and trauma for those without I/DD into the “social stories” methodology.

Looking Ahead: Recommendations for Future Systems Change Work for Researchers, Advocates and Policy Makers

Needed Research

- **Research adapting TF-CBT for people with I/DD:** Research studies focused on the best way to adapt Trauma Focused-Cognitive Behavioral Therapy (TF-CBT) for individuals with I/DD experiencing trauma and/or sexual assault and/or any type of abuse. There is a need for guidance and resources about treatment methodologies for individuals with I/DD who also have experienced trauma and sexual assault. Tools and resources need to reduce the silo where people with I/DD are not included in the research. This population needs to be included with others so that tools and resources work for them as well as other populations.
- *Action Steps:*
 - Perform a literature review to:
 - Identify any controlled research studies on effectiveness of approaches that adapt TF-CBT for the population of those with I/DD experiencing trauma
 - Identify any research that tests existing adaptations of TF-CBT
 - If Literature review shows that there is
 - Existing research on adaptations and effectiveness of TF-CBT for people with I/DD better publicize research.
 - Not existing research - conduct studies on adaptations and effectiveness of TF-CBT for people with I/DD, ensuring cultural diversity and equity issues.
 - Develop Implementation Plans and research provision of plans to identify how to move research quickly more effectively into practical use.
- Adapt existing TF-CBT sexual education modules to include individuals with I/DD
- Develop Structured Assessment to gauge the needs of individuals with I/DD who experienced abuse and assault.
 - Adapt (if already exists), or develop, a structured assessment to guide treatment planning that meets the needs of individuals with I/DD who had experienced abuse or assault. The assessment should be relevant for individuals with I/DD who have challenges with communication. Conduct research on the assessment to ensure the tool is evidence-based. The tool should be systematic enough to be reliable yet flexible enough to accommodate a wide range of individual cognitive variability.
- *Adapt Existing Best-Practice Treatment Modalities to Serve Individuals with I/DD:*
 - A potential strategy that could be utilized to speed up identifying and adapting key treatment approaches to identify best practice for individuals with DD experiencing trauma includes:
 - Mapping typical effective components of trauma treatment (not specifically for those with I/DD) then,
 - Mapping typical effective components of treating/supporting individuals with I/DD (not specifically trauma-related), finally
 - Overlay the mapping products into a new adaptive tool that may serve individuals with I/DD experiencing trauma

Waiting 20 years to move research into action takes too long. Study effective implementation to bridge the gap between an improved body of knowledge to improving actual lives

EDUCATION/TRAINING

- ***Advocate policymakers to require training about preventing, identifying, and treating sexual violence against people with I/DD.*** Ensure required training includes steps to support a victim while getting a victim appropriate treatment should abuse occur. Training should be required for:
 - People who have frequent contact, or provide direct support for, people with I/DD such as:
 - Behavioral health professionals (BHPs). Policymakers to include Department of Education, Department of Health and Human Services, and legislators.
 - School personnel on this issue. Policymakers to include Department of Education and legislators.
 - Individuals with I/DD themselves
 - Families, guardians
 - Home care, such as group homes, nursing homes, and shared-living, providers
 - Daycare providers
 - Case Managers
 - Adult Protective Services
 - Medical school students.
 - Practitioners of the healing arts
 - Practitioners already knowledgeable about I/DD as they likely will need more training on treatments of trauma and sexual abuse.
- ***Develop and disseminate broad-based education about sexual abuse/assault of individuals with I/DD including, but not limited to, messaging and information:***
 - That includes recognition that this population of people with I/DD are sexual entities and are routinely abused.
 - Identifying the signs and symptoms of potential abuse.
- ***Develop and disseminate resources to guide in modifying how to integrate into general sex education how to, and the importance of, including individual with I/DD in classes.***
- ***Develop and maintain a resource list of professionals who have expertise in both treating trauma AND treating those with I/DD***

POLICY

- ***Advocate that MaineCare “enhanced payments” for several evidence-based practices (including for Trauma Focused-Cognitive Behavioral Therapy-TF-CBT) in Maine.***
- ***Advocate that DHHS promulgate relevant rules that mandates education for mental health practitioners on how to provide treatment and support survivors of trauma and sexual abuse/assault who also have I/DD.***
- ***Educate policymakers about barriers, and promulgate policy to mitigate barriers, to accessing behavioral, mental, and physical healthcare for people with I/DD.***

Recommended References

- Autism Speaks (2022) **Recognizing and Preventing Abuse** <https://www.autismspeaks.org/recognizing-and-preventing-abuse> Accessed October 2022
****Notes: Website with expert insights on practical areas related to communication with people who have ASD, prevention of abuse, appropriate services and tools to recognize and prevent abuse.*
- Beail, Nigel, Skelly, Alan & Frankish, Pat (2021) **Trauma and Intellectual Disability: Acknowledgement, Identification and Intervention** (book) Pavilion Publishing & Media Ltd ISBN: 1914010590
- Center for Healthcare Strategies (2021) **Trauma-Informed Care Implementation Resource Center** <https://www.traumainformedcare.chcs.org/> Accessed October 2022
- Earl, Rachel K., Peterson, Jessica L. Arianne S. Wallace, Fox, Emily, Ma, Ruqian, Pepper, Micah, Haidar, Ghina (2017) **Trauma and Autism Spectrum Disorder: A Reference Guide** [trauma and autism spectrum disorder \(tfcbt.org\)\(chrome-extension://efaidnbmnnnibpcajpcqlclefindmkaj/https://tfcbt.org/wp-content/uploads/2019/05/Bernier-Lab-UW-Trauma-and-ASD-Reference-Guide-2017.pdf\)](trauma%20and%20autism%20spectrum%20disorder%20(tfcbt.org)(chrome-extension://efaidnbmnnnibpcajpcqlclefindmkaj/https://tfcbt.org/wp-content/uploads/2019/05/Bernier-Lab-UW-Trauma-and-ASD-Reference-Guide-2017.pdf) Bernier Lab, University of Washington Center for Human Development and Disability Accessed October 2022
- Fleming PhD, Tabitha C, Risch PhD, Elizabeth (2022) **Adapting TF-CBT for Youth with ID/DD** PDF file of slide presentation https://oklahomatfcbt.org/wp-content/uploads/2022/05/TF_Advanced_IDD_2022_Final_handout.pdf OUHSC Center on Child Abuse and Neglect/Child Study Center. PowerPoint Presentation
****Notes: Great slides and resources/references at end are helpful.*
- Hughes RB, Robinson-Whelen S, Davis LA, Meadours J, Kincaid O, Howard L, Millin M, Schwartz M, McDonald KE; Safety Project Consortium. (2020) **Evaluation of a Safety Awareness Group Program for Adults With Intellectual Disability**. Am J Intellect Dev Disability doi: 10.1352/1944-7558-125.4.304. PMID: 32609805.. ****Note: Article covers self-awareness program for women with diverse disabilities in partnership with people with I/DD. Valuable as part of individual program development and shared decision making. Research used a multi-modal approach to teaching people with I/DD about: safety, self-efficacy, and prevention.*
- Illinois Imagines Project (March 2017) **Guide for Counselors for Working with Survivors with Intellectual Disabilities and Autism** ICASA [GUIDE FOR COUNSELORS FOR WORKING WITH SURVIVORS WITH INTELLECTUAL DISABILITIES AND AUTISM](GUIDE%20FOR%20COUNSELORS%20FOR%20WORKING%20WITH%20SURVIVORS%20WITH%20INTELLECTUAL%20DISABILITIES%20AND%20AUTISM) (chrome-extension://efaidnbmnnnibpcajpcqlclefindmkaj/https://icasa.org/uploads/documents/illinois-imagines/Counseling-Guide-3-18-mini.pdf)_Accessed October 2022)
- Illinois Imagine Project (December 2018) **Advocate Guide for Working with Survivors with Intellectual Disabilities and Autism** ICASA. <https://icasa.org/uploads/documents/illinois-imagines/advocate-Guide-12-18-mini.pdf> Accessed October 2022
****Notes: Good resource for counselors. Universal principles from preparation to action. Strong for longitudinal counseling. This is part of a larger product specific to providing advice for counselors. This is a very specific and comprehensive (177 pages) resource that can be used cover-to-cover or just access the chapter of interest.*

National Child Traumatic Stress Network (2021) **Webinar series: Tailoring Trauma-Focused Cognitive Behavior Therapy for Children with I/DD** <https://www.nctsn.org/resources/tailoring-trauma-focused-cognitive-behavior-therapy-for-children-with-IDD> Accessed October 2022

National Child Traumatic Stress Network (NCTSN) (2022) **Resources List: Trauma Response for Children with Developmental Disabilities** *NCTSN Resources | The National Child Traumatic Stress Network.* (<https://www.nctsn.org/what-is-child-trauma/populations-at-risk/intellectual-and-developmental-disabilities/nctsn-resources>) Accessed October 2022

National Sexual Violence Response Center (NSVRC) (2022) **Victim Centered Approaches: People with Disabilities** <https://www.nsvrc.org/sarts/toolkit/6-6> Accessed October 2022
****Notes: Helpful toolkit with list of resources at the end. Includes short video with principles of working with individuals with disabilities.*

Pedgrift, K., Sparapani, N. (2022) **The development of a social-sexual education program for adults with neurodevelopmental disabilities: starting the discussion.** <https://doi.org/10.1007/s11195-022-09743-1> Accessed October 2022
****Note: Reports on the development of a prevention program named the Social-Sexual Education Project. Focus on development of healthy relationship building, recognition of abuse/coercion. Input in evaluation and content by people with DD. Evaluative components included structured interviews. Lessons on program development, implementation.*

Pennsylvania Coalition Against Rape (PCA) (2022) **Advocating for Victims with Intellectual/Developmental Disabilities During a Sexual Assault Forensic Examination** https://pcar.org/sites/default/files/resource-pdfs/tab_2011_summer_advocatingforvictimswithintellectualdevelopmentaldisabilitiesduringsafepar1.pdf Accessed October 2022
****Notes: Good resource for counselors working with individual with I/DD when topic of sexual assault or abuse comes up.*

Riechers, Victoria (2021) **Responding to Sexual Assault Survivors with Disabilities Parts 1 & 2** [Responding to Sexual Assault Survivors with Disabilities Part 1](https://www.youtube.com/watch?v=4kJbhpJv9rE) (<https://www.youtube.com/watch?v=4kJbhpJv9rE>) and [Responding to Sexual Assault Survivors with Disabilities Part 2](https://www.youtube.com/watch?v=kK4EmdwVtxA) (<https://www.youtube.com/watch?v=kK4EmdwVtxA>) Arizona Coalition to End Sexual and Domestic Violence Accessed October 2022
****Notes: Series of training modules including two modules specific to how to support individuals with disabilities who are survivors of sexual assault. The intended audience includes: health care responders (including clinicians), social workers, and law enforcement. American Sign Language interpreters provided for all videos. This series includes guidance on culturally responsive services to increase safety and trauma-informed healing. Videos focus on sexual assault from neurobiological, psychosocial response, approach to questioning, and includes survivor perspectives.*

Sexual Assault Nurse Examiner (SANE) (2022) **SANE Program Development and Operation Guide** [Introduction to the SANE Program Development and Operation Guide; Sexual Assault Nurse Examiner](https://www.ovcttac.gov/saneguide/introduction/) (<https://www.ovcttac.gov/saneguide/introduction/>) Office for Victims of Crime, Office of Justice Programs Utah Accessed October 2022

Shapiro, Joseph (2018) **The Sexual Assault Epidemic No One is Talking About** The Sexual Assault Epidemic No One Talks About : NPR (<https://www.fris.org/Resources/Toolkit-Disabilities.html>) Accessed October 2022

****Notes: Powerfully voiced journalism with survivor stories. It is compelling, to the point, and if clinicians are encountering this truth for the first time this would be an easy tool to motivate them to dig in more and treating the topic and situation with the necessary gravity.*

Washington Coalition of Sexual Assault Programs-(WCSAP) (2020) **Supporting People with Intellectual and Developmental Disabilities with Trauma Histories** Supporting People with Intellectual and Developmental Disabilities with Trauma Histories (<https://www.wcsap.org/resources/webinars/advocacy/focus-areas/disability/supporting-people-intellectual-developmental>) Accessed October 2022

****Notes: Excellent overview of things to think about (i.e. diverse experiences of social conditioning) when working with this population. Focuses on principles. This resource is not specific to sexual assault or treatment strategies but provides information more broadly on working with persons/survivors with I/DD. Not specifically for therapists or clinicians.*

West Virginia Foundation for Rape Information and Services (2020) **S.A.F.E. Training and Collaborative Tool Kit** <https://www.fris.org/Resources/Toolkit-Disabilities.html> Accessed October 2022

**** Notes: Covers general knowledge of sexual assault, integration of specific materials into social service delivery system, evaluative tools for assessment of social service system, generalities associated sexual assault assessment, approach, forensic evaluation, specifics related to disability approach to the sexual survivor, including communication, accommodations, co-occurring mental illness. Comprehensive across the spectrum of care. Toolkit includes programming, sexual assault 101 information, empowerment wheels. Good resource to fill in provider's gaps in knowledge.*

Appendix A.

Community of Praxis Participants

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<p>Shawn Kalbach, Ph.D., Licensed Psychologist Assistant Medical Director, Edmund N Ervin Pediatric Center, MaineGeneral Shawn.kalback@mainegeneral.org</p>
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<p>Alyssa Siegel, MD General Pediatrician, Children’s Hospital of Philadelphia (COHP) Clinical Director of CHOP NJ Transition to Adult Coordinated Care Clinical Assistant Professor of Pediatrics, Univ of Pennsylvania Medical School SiegelA@chop.edu</p>
<p>Matthew Siegel, MD Vice President of Medical Affairs, Maine Behavioral Healthcare/MaineHealth Maine Medical Center Research Institute Matthew.Siegel@mainehealth.org</p>

Appendix B

. Advisory Committee Participants

<p>Carrie Woodcock Executive Director Maine Parent Federation cwoodcock@mpf.org</p>
<p>Rachel Dyer, MBA Associate Director Maine Developmental Disabilities Council Rachel.M.Dyer@maine.gov</p>
<p>Lisa Råvar, Prevention & Community Change Coordinator, Maine Coalition Against Sexual Assault lisa@mecasa.org</p>
<p>Stacy Giberson Speaking Up For Us</p>

Appendix C. Additional Resources

- Amborski, Amylee Maihot, Bussieres, Eve-Line, Joyal, Christian C et. Al. (2021) **Sexual Violence Against Persons with Disabilities: A Meta-Analysis** Sage Journals (<https://journals.sagepub.com/doi/10.1177/1524838021995975>) Accessed October 2022
***Notes: Evidence-based analysis of rates of sexual assault with comparison between those with and without disabilities plus evaluation of different variables influencing abuse. Odds of global sexual trauma included with comparisons and contrast.
- Attachment, Regulation, Competency (ARC) (2022) **What is the ARC? What is ARC?** (<https://arcframework.org/what-is-arc/>) Accessed 2022
- California Coalition Against Sexual Assault (2010) **Supporting Sexual Assault Survivors With Disabilities** *Supporting Sexual Assault Survivors with Disabilities* (chrome-extension://efaidnbmnnnibpcajpcgclefindmkaj/<https://www.calcasa.org/wp-content/uploads/2010/12/Survivors-with-Disabilities.pdf>) Accessed October 2022
***Notes: Very helpful section starts page 11.
- Cohen, Judith A, Mannarino, Anthony P, Deblinger, Esther (2012) **Trauma Focused CBT for Children and Adults**. The Guilford Press
***Notes: Includes a brief article by Christina Grosso that give tips and strategies in how to adapt TF-CBT for the IDD population.
- Disability Rights Ohio (2015) **Sexual Abuse of Individuals with Developmental Disabilities Brief One: Contributing Factors** SEXUAL ABUSE OF INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES (chrome-extension://efaidnbmnnnibpcajpcgclefindmkaj/https://www.disabilityrightsohio.org/assets/documents/dro_sexual_abuse_brief1_final.pdf) Accessed October 2022
***Notes: Data-driven meta-analysis that complements actionable resources. Includes fact sheets.
- Elevatus Training (2022) **Sexual Rights: Safety, empowering self-advocates to keep themselves safe** <https://www.elevatustraining.com/sexual-rights-safety-empowering-self-advocates-to-keep-themselves-safe/> Accessed October 2022
***Notes: Not specific to abuse.
- Elevatus Training (2022) **Elevatus Training** <https://www.elevatustraining.com/> Accessed October 2022
*** Notes: Elevatus' website claims that they are national leaders in the field of sexuality and I/DD. They offer evidence and trauma informed curriculum, online training, in-services and workshops to help professionals, educators, self-advocates and parents skillfully and confidently navigate the topic of sexuality.
- End Abuse of People with Disabilities (2022) **Providing Accessible and Effective Services to Survivors of Sexual Assault with Disabilities** End Abuse of People with Disabilities (<https://www.endabusepwd.org/resource/providing-accessible-and-eendabusepwdeffective-services-to-survivors-of-sexual-assault-with-disabilities/>) Accessed 2022
*** Notes: Excellent video with perspectives from survivors covering sexual violence. Courageous stories. Provides insight (including stories from victims) but not specific guidance for therapists

- Gray, Carol (2022) **What is a Social Story** *What Is A Social Story? - Carol Gray*
(<https://carolgraysocialstories.com/social-stories/what-is-it/>) Accessed 2022
- Hingsburger, Dave (1996) **Hand Made Love: A guide for Teaching about Male Masturbation Through Understanding and Video** Diverse City Press Accessed 2022
**** Notes: Good information though not focused on survivors.*
- Lieneman, Corey C, Brabson, Laurel A, Highlander, April, Wallace, Nancy M, McNeil, Cheryl B (2017)
Parent-Child Interaction Therapy: current perspectives
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5530857/> Accessed 2022
- Mahoney, Amanda, Poling, Alan (2011) **Sexual Abuse Prevention for People with Severe DD** *Journal of Developmental and Physical Disabilities* <https://link.springer.com/article/10.1007/s10882-011-9244-20> Accessed October 2022
****Notes: Introductory article covering select populations in diverse settings (institutions, foster care, etc), that are not well supported in terms of agency and independence. Includes staff training. Geared to prevention. Requires purchase.*
- National Child Traumatic Stress Network (2022) **Parent-Child Interaction Therapy**
<https://www.nctsn.org/interventions/parent-child-interaction-therapy>. Accessed October 2022
****Notes: Targeted population is 2-7 years old; could be appropriate for older aged children with DD. Provides tools to families as a mean to support emotional/behavioral regulation*
- National Child Traumatic Stress Network (2022) **Parent Child Interaction Therapy Training Guidelines**
https://www.nctsn.org/sites/default/files/interventions/pcit_training_guidelines.pdf Accessed October 2022
****Notes: Targeted population is 2-7 years old; could be appropriate for older aged children with DD. Provides tools to families as a mean to support emotional/behavioral regulation*
- National Child Traumatic Stress Network (2022) **Trauma Interventions Modality Overview**
Interventions | The National Child Traumatic Stress Network
(<https://www.nctsn.org/treatments-and-practices/trauma-treatments/interventions>) Accessed October 2022
- National Association of Dual Diagnoses (NADD) (2022) <https://thenadd.org/> Accessed October 2022
- National Sexual Violence Resource Center (2022) **Victim Centered Approaches Toolkit 606**
(<https://www.nsvrc.org/sarts/toolkit/6-6>) Accessed October 2022
****Notes: Website features different aspects of interpersonal violence and includes people with disabilities. Data, definition, policy, people-first language, diversity. Training materials provided, including short videos for 1st responders, including survivor perspective. Information is not significantly detailed, but important for 1st responders, since this group of professionals rarely receives information about people with disabilities, yet clearly their front-line position necessitates exposure to this marginalized*

Rape, Abuse & Incest National Network (RAINN)(2022) **Rape, Abuse Incest National Network-Resources** https://www.rainn.org/?_ga=2.52333999.788298973.1659372726-1609149329.1659372726
Accessed October 2022

Rape, Abuse & Incest National Network (RAINN)(2022) **Sexual Abuse of People with Disabilities** [Sexual Abuse of People with Disabilities | RAINN \(https://www.rainn.org/articles/sexual-abuse-people-disabilities\)](https://www.rainn.org/articles/sexual-abuse-people-disabilities) Accessed October 2022

Saunders, Cathy Lynn (2019) **My Name is Cathy Lynn-A Love Letter From Me To You** (2019)
Independently published book

****Note: A collection of poems through which the author shares her experience of life as an African American woman with a disability growing up in Chicago and the encounters that formed her development as a poet: adoption, spirituality, sisterhood, sexual assault, and survival.*

SexEdMart (2022) **Sex Ed Mart** [Special SexEd \(https://sexedmart.com/product-category/special-needs-resources/\)](https://sexedmart.com/product-category/special-needs-resources/) Accessed October 2022 ****Notes: Offer products specifically designed to teach safe sex and self-advocacy to people with I/DD. Not specific to abuse.*

Special Needs Resource (2022) **Make Your Own Social Stories** [12 Computer Programs, Websites And Apps For Making Social Stories - Friendship Circle - Special Needs Blog](#) Accessed 2022

South Dakota State University (2022) **Counseling Those with Developmental Disabilities** [Counseling Those With Developmental Disabilities | South Dakota State University \(https://www.sdstate.edu/counseling-and-human-development/counseling-those-developmental-disabilities\)](https://www.sdstate.edu/counseling-and-human-development/counseling-those-developmental-disabilities) Accessed 2022

Therapist Certification Program (2022) **Trauma-focused Cognitive Behavioral Therapy (TF-CBT)** [About Trauma-Focused Cognitive Behavior Therapy \(TF-CBT\) - Trauma Focus Cognitive Behavioral Therapy Certification Program \(https://tfcbt.org/about/\)](https://tfcbt.org/about/) Accessed October 2022
****Notes: Quick Overview of TF-CBT model with good basic fact sheets that can be included.*

Thomas-Williams, Cierra Olivia (2022) **Providing Accessible and Effective Services to Survivors of Sexual Assault with Disabilities** <https://www.endabusepwd.org/wp-content/uploads/2022/04/Providing-Accessible-and-Effective-Services-to-Survivors-of-Sexual-Assault-with-Disabilities.pdf> Accessed 2022
**** Notes: Interesting overview with good detailed info; not specific to treatment.*

MDDC is a partnership of people with disabilities, their families, and agencies which identifies barriers to community inclusion, self-determination, and independence. Its mission is creating a Maine in which all people are valued and respected because we believe communities are stronger when everyone is included. <https://www.maineddc.org/>

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