Sexual Violence Told Through Lived Experiences of Survivors, Families, and Professionals

The impact of sexual violence on people with intellectual and developmental disabilities.

THE UNIVERSITY OF ARIZONA
COLLEGE OF MEDICINE TUCSON
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RESEARCH PROJECT TEAM

This project was led by Lynne Tomasa, PhD, MSW, FAAIDD, an affiliate faculty with the University of Arizona Sonoran Center for Excellence in Disabilities. Special acknowledgement to Philip Johnson, PhD, CRC, formerly with the University of Arizona College of Education Rehabilitation and Mental Health Counseling Program who provided valuable assistance with data collection, analysis, and editing. The student interns on this project included Sandra Siegle, Louis Fazio, Amber Hansen, Vanessa Zuber, Analisa Terán and Anna Cargile Avila. Artwork and designs by Bria Luu.

CONTACT

Report prepared by Lynne Tomasa, PhD, MSW, FAAIDD, from the University of Arizona Department of Family and Community Medicine Sonoran Center for Excellence in Disabilities. Contact information: ltomasa@arizona.edu.

This report is dedicated to the brave individuals who participated in the interviews and shared their experiences in order to increase our awareness about sexual violence and its impact. We must believe what persons with intellectual and developmental disabilities (I/DD) tell us through their words and behaviors. Sexual violence risk reduction and healing requires collaboration and transparency.

CONTENT WARNING

The report is for an adult audience. The content of this report includes honest, vivid, and painful stories from survivors, families, and professionals with extensive experience working in the disability field. The report includes graphic descriptions of sexual violence against persons with disabilities. The information may trigger difficult emotions and memories. If you are unsure how you may react to graphic descriptions or have any concerns, please do not read this report.

Take the time to care for yourself and the people with disabilities that you support.

Here are some national and Arizona resources.

- Suicide Hotline: Call 988. 988lifeline.org
- RAINN or Rape, Abuse Incest, National Network - National Sexual Assault Hotline: Call 800-656-4673 or chat online at rainn.org
- National Domestic Violence Hotline: Call 1-800-799-7233. thehotline.org
- StrongHearts Native Helpline: Call 844-762-8483. strongheartshelpline.org
- VictimConnect Resource Center: Call 1-855-484-2846 (weekdays). victimconnect.org
- The Deaf Hotline: Call 1-206-812-1001. thedeafhotline.org
- AZ Coalition to End Sexual and Domestic Violence/ACESDV: Call 602-279-2980. acesdv.org
- Southern Arizona Center Against Sexual Assault/SACASA: Call 520-327-7273. sacasa.org

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Introduction:

The “Untold Stories” Research Project

The research project was approved by The University of Arizona Human Subjects Protection Program (HSPP) after a full committee review.

This study had the following objectives:

- Increase public awareness of what National Public Radio (NPR) identified as the “Hidden Epidemic of Sexual Assault” (2018).
- Report on the “lived experiences” of sexual violence survivors, families, and professionals in Arizona.
- Identify strategies that complement and expand on Arizona’s efforts to address this crisis.

The survivors, family members, and professionals interviewed for this report emphasized that more can be done to address the disturbingly high rate of sexual violence among people with intellectual and/or developmental disabilities (I/DD). The terms “victim” and “survivor” are both used in this report to acknowledge that each person may identify with one or both terms when sharing their experience. The definition of I/DD used in research, datasets, and service eligibility requirements is not consistent. In Arizona, the Department of Economic Security - Division of Developmental Disabilities (DDD) provides supports to individuals with the diagnosis of autism, cerebral palsy, epilepsy, cognitive/intellectual disability, and down syndrome.

Participants shared their lived experiences so that others will understand that it “can happen anywhere and to anyone.” Sexual violence affects children, men, and women of all ages. An individual may be abused repeatedly by the same perpetrator or on multiple occasions by different perpetrators. Many adults first experience violence and trauma as a child. The survivors’ stories reveal that healing from sexual trauma takes time, support, and community engagement.

The report is divided into five parts and includes 1) Lived Experiences of People with I/DD, 2) Families Share Their Stories, 3) Professionals Share Their Experiences, 4) The Community Responds, and 5) Project Summary and Recommendations. The data were collected through interviews and an online survey. Participants' personal stories are shared in their own words throughout this report.

Understanding the Data on Sexual Violence

This section provides a definition of sexual violence and what data can "tell us" and "not tell us" about sexual violence. It shows the importance of asking about and listening to lived experiences. The voices will underscore the urgency and importance of taking a close look at underreporting of sexual violence for people with I/DD.

What is Sexual Violence?

Sexual Violence occurs when someone forces, controls, threatens, bribes, pressures, tricks or manipulates a person into unwanted sexual contact or attention. It is done without their consent, permission, or approval. Sexual violence includes the following crimes: sexual assault, sexual abuse, and physical violence. The legal definition of these crimes is different from state to state.

There are many forms of sexual violence that include physical or non-physical touch, words, attention, or language. These include sexual assault, rape, attempted rape, child molestation, incest, intimate partner violence, sexual harassment, exploitation, inappropriate touching of one's body or genitals, watching someone in a private act without their knowledge or permission, and sexual exploitation or trafficking. Definitions and examples of sexual violence can be found at:

The Arc Report - *People with Intellectual Disabilities and Sexual Violence*: bit.ly/thearc-org

RAINN (Rape, Abuse & Incest National Network) website - *Sexual Assault:* bit.ly/rainnsa

National Sexual Violence Resource Center Factsheet - *What Is Sexual Violence*: bit.ly/nsvrcfactsheet

The Prevalence of Crimes Against Persons with Disabilities

In 2018 National Public Radio (NPR) published the Special Series *Abused and Betrayed*. Included was investigative reporter Joseph Shapiro's *The Epidemic of Sexual Assault.* These are crimes that often go "unrecognized, unprosecuted and unpunished." Data from unpublished U.S. Department of Justice Government documents found that "people with I/DD are sexually assaulted at rates at least seven times that of people without disabilities." It also found that people with intellectual and developmental disabilities are more likely to be sexually assaulted by someone they know, at any time of day, and in all settings.

"The Sexual Assault Epidemic
No One Talks About"
https://n.pr/3VTAD6B

The data about sexual violence can be overwhelming and difficult to understand. It is important to look at what is being measured, how information is collected, the age of the individuals sampled, and who is reporting the sexual violence experience. The Bureau of Justice Statistics (BJS) National Crime Victimization Survey (NCVS) is the nation's primary source of information on criminal victimization. It is an annual sample of U.S. households that include individuals aged 12 or older who are living among the general population. It excludes those who live in institutions (correctional facilities for adults and juveniles, nursing or skilled nursing facilities, residential schools, and hospitals). The NCVS acknowledged that exclusion of these institutional data results in an undercount of violence against persons with disabilities. The six disability categories included hearing, vision, cognitive, ambulatory, self-care, and independent living. The BJS published additional data in the Crime Against Persons with Disabilities 2009-2019 report in 2021.

References:

- National Crime Victimization Survey(NCVS). bjs.ojp.gov/data-collection/ncvs#xj29kl
- Harrell,E.(2021).Crime against persons with disabilities, 2009-2019-statistical tables (NCJ 301367). bjs.ojp.gov/content/pub/pdf/capd0919st.pdf

Research Study Participants

Twenty-six interviews were completed from January to September 2022. Data analysis took a significant amount of time to transcribe, review, and code the data. Of the 26 participants, eight were adult survivors of sexual violence, three were family members, and 15 were disability service providers and professionals with a history of supporting individuals with I/DD in Arizona. The interviews were approximately 60 to 90 minutes long. They were recorded and transcribed.

Survivors of sexual violence with disabilities self-identified as having autism, cerebral palsy, learning disabilities, and a dual diagnosis (having an intellectual disability with an anxiety disorder or bipolar disorder). At the time of their interview, six of the survivors lived in their own home and two lived in their parents' home. Family members were mothers of children with I/DD. The 15 professionals worked in the disability field for 4 to 40-plus years in various state and community agencies. They held positions as a case manager, program manager, direct support provider, vocational rehabilitation counselor, day program supervisor, administrator, advocacy worker, legal guardian, attorney, quality assurance staff, social worker, juvenile detention staff, prison staff, and crisis worker. Additional demographics of all research participants are reported in Table 1 below.

Interview Participant Demographics		**Survivors N=8**	**Family N=3**	**Professionals N=15**
Age Range		29 to 58	39 to 63	22 to 68
Race/Ethnicity				
	Hispanic/Latinx/o/a or Chicano/a	2	-	1
	Hispanic/Latinx/o/a or Chicano/a & White	1	-	-
	White or European	4	3	12
	Mixed	1	-	-
	White/Native American	-	-	1
	Other (American)	-	-	1
County	Cochise	-	-	2
	Pima	4	1	11
	Maricopa	3	2	2
	Yuma	1	-	-
Gender	Female	5	3	12
	Male	3	-	3

Part One:

Lived Experiences of People with I/DD

> It's always so hard to hear the stories. But it's happening all the time and so you know the more that we hear about them, the more that we talk about them, the more of a difference we're making. And so, to me, it's really important to hear the stories.
>
> - Study Participant

Individuals with intellectual/developmental disabilities are at an increased risk for sexual violence and abuse. Survivors can experience multiple incidents of abuse during their lifetime. They are often afraid to disclose their abuse and it is common for others (i.e., family members, health care providers, friends, police, and prosecutors) to question the credibility of a person with I/DD if they do report it. Survivors may experience short and long-term effects from sexual abuse. These include depression, guilt, nightmares, suicidal ideation, shame, and anger. It can impact a person's ability to form personal, romantic, and workplace relationships.

Stories of Sexual Violence

These stories document that individuals were victims of multiple incidents of sexual violence by the same or different individuals. Some experienced one incident, while others experienced numerous incidents over many years. Every incident was non-consensual. The lived experiences started when the individual was a young child, teen, or adult. Here are their important stories.

Male Survivor – 1

Sexual violence started when the survivor was five years old and occurred on multiple occasions over a two-year period. The perpetrator was a babysitter who asked the survivor to “stimulate her” after she took a shower. Survivor complied because, “You know, I didn’t know what I was doing.” One day the babysitter disappeared. Survivor is very aware of the complexities of “the world that disabled people live in where they have to trust caregivers and sometimes you don’t have a choice” of caregivers.

Male Survivor - 2

Survivor needs support with personal care and was a member of a performance group. An acquaintance performed nonconsensual oral sex on the victim who was sleeping. Survivor was “afraid of the consequences of telling someone.” The perpetrator also victimized other people.

Second incident: Domestic violence included spousal abuse where it “felt like she could dominate me because she was able to physically lift me.” Survivor desires to have a “meaningful romantic relationship.”

Male Survivor - 3

Survivor was abused by four different individuals. He was raped by a male he met while staying at a hotel, by a personal care assistant, a colleague he dated for five years, and by another personal care assistant. One personal care assistant touched the survivor in inappropriate and non-consensual ways while providing caregiving services. The personal care assistant pulled the sheet off to help and “The first thing he would do is, fondle me, and such.” This went on for “weeks.” The survivor realized that in a relationship, “certain things were consensual, but not everything was consensual.” These experiences still affect him and “For a long, long time, I thought it was my fault because I shouldn’t have asked him to help me.”

Female Survivor - 1

Survivor lived in a “community living program” (apartment complex) where she received in-home support services. The male perpetrator lived in the same apartment complex with his wife and would bring over food. Over time, the male neighbor began to pressure the individual to kiss him and have physical contact. When the assault occurred, survivor was experiencing a “manic state with psychosis.” Survivor told him, “No more.” At one point, the perpetrator “tried to force penetration.” He had carried her to the bathroom and then “ran away” when someone came into the apartment.

Female Survivor - 2

They met at work. Dates with the perpetrator “were always at his place.” There were numerous instances of abuse that included: threats with a knife for not doing what he told her to do; withholding food; physical hitting, mocking and

calling her names; isolation from family and friends; rape while she was sleeping; forcing her to have oral sex; and forcing her to clean his apartment. The perpetrator “used religion as an excuse to abuse” and stalked her after she left him. Panic attacks remind her of the day she was raped. It took a long time for her to tell her family. She shares her story and “I’ve realized the more I tell my story, the more I’m being healed.”

Female Survivor – 3

Survivor experienced bullying by a “group of a few girls” that started in elementary school because “they knew I was different.” The bullies would “do mean things to upset me” and “it was beyond bullying.” Their behaviors “became more sexual in nature” in the sixth grade.

At recess they would ask the individual to go into the bathroom and keep the door open so that other girls could join in and watch. Other incidents included telling the individual to put her legs up on the grab bars, “And they would imitate sexual movements, and I didn’t like that.” The bullies told the survivor, “To do certain things, like touch myself in certain areas while the people watched and then try to come and touch me there.” Survivor did what the girls said because she believed that they were going to harm her family. Perpetrators went to the same junior high and high school and the abusive behaviors escalated. They told the individual to “slit your wrists and bleed out” when she was feeling over-stimulated. Perpetrators used threats to keep the survivor from reporting their behaviors. Threats included “Don’t say anything or you’re going to watch us kill your brothers and your parents” and her cat. The survivor told a resource officer at the school, and he acted immediately.

Survivor also had a friendship that became a romantic relationship. Her boyfriend wanted to be more intimate, but she was not ready to engage in certain sexual behaviors. She told him, “I don’t want anything that would be more intimate until after we are married because we agreed upon that.” Over time, “It just started getting worse, and that’s when it got scary because he was saying he was respecting me and he would stop, and he wanted to go further.” Her service dog “started getting uncomfortable around him.” Boyfriend told her that he would kill himself if she left him.

Female Survivor - 4

Survivor met her mother’s boyfriend when she was 11 years old. For the next few years, he “actually groomed me to trust him…You know, by the time I was 13, we kind of developed more of a friendship, like a father-daughter bond started.” Perpetrator “was a very convincing individual. He made friends with all my friends from school. He made himself the cool dad. Anything you could have possibly ever wanted from your parents or your stepparents, that’s exactly who he was.” He “had all the perfect charismatics of a boyfriend and dad in one.” She thought that he loved her.

Sexual abuse started at perpetrator’s house when she was 15 years old. She described the experience as, “I was on medication and we had - you know, we had intercourse…I was so out of it. And I was literally like, ‘What the hell just happened?’ I wasn’t against it or for it, but I just - I wasn’t even mentally in a state where I could consent.” She reported the abuse when she was 18 years old. She figured out that sex offenders are not just monsters lurking, "they’re literally so good at hiding it.”

Female Survivor – 5

Survivor sat at a computer and the perpetrator “started sitting next to me and started touching my legs…He just continued doing it and I didn’t feel comfortable telling anybody.” Abuser “kept doing it that same year at different places and at different museums we would go to.” She “didn’t feel comfortable telling anybody.”

There was also an incident that happened at summer camp when she was about 15 years old. The camp counselor was helping her take a shower and she “started touching, like, my private parts and asked me if it tickled.” The camp counselor kept “doing it over and just saying, ‘Does it tickle, and does that feel good?’” Survivor gets scared of “being alone in different areas because I don’t know what somebody would like to do because they feel like they can do things because I am not as able as other people are.”

The Impact of Sexual Violence and Abuse

The symptoms of trauma experienced by victims of sexual violence may last for months or years, or persist throughout their lives. These symptoms, such as recurrent memories of the abuse, upsetting dreams or nightmares, and emotional blunting severely impact a victim's mental health, quality of life, feelings of self-worth, sense of trust, and ability to maintain and build new relationships. Through the words and emotions shared by the survivors, we hear the deep and lasting impact of sexual violence.

Depression and Anxiety

Individuals experienced a "severe depressive phase" that took "a long time to recover." The trauma of one person's experience made her "hypervigilant" and "more cautious to have male friends in her apartment." Survivors continue to experience panic attacks that "always reminds me of the day I was raped." Their experiences also impact their daily activities and routines. One victim shared:

> "I can even remember not being able to shower. I remember not wanting to wake up. I remember not being on time to work or anything. That was how that was for a very long time."

For another survivor:

> "The first week I reported him, I ended up going into a psychiatric facility because I couldn't manage the emotions. I couldn't go back to school. I couldn't do anything."

Fear and Shame

Victims are afraid that their perpetrator and somebody else will harm them. The feelings of fear and shame impact other aspects of their lives. Some are afraid to leave their perpetrator because "I had heard so many stories of women being killed, when they were trying to leave." One survivor was scared that "somebody's going to suddenly turn into somebody who is bad and wants to hurt me."

One survivor was doing well but still feeling vulnerable and scared of being alone, "because I don't know what somebody would like to do because they feel like they can do things because I am not as able as other people are." These emotions and the trauma experienced make it difficult to talk about what happened. A person can be afraid of the consequences of telling others because "there was no proof that it happened." For one person, "I was kind of ashamed about it for a little bit 'cause I was like, I should've told somebody beforehand because that person could, you know, hurt somebody else." Talking about what happened is difficult. According to one survivor, "I didn't feel comfortable telling anybody until later – a long time later – I told my mom."

Self-Blame

Individuals with disabilities may have experienced other traumatic events or behaviors in their life. When a person has been told repeatedly that they are not good enough, these experiences have a lasting impact. Asking for help is not a bad thing to do but for one person, "For a long, long time, I thought it was my fault because I shouldn't have asked him to help me." Victims blame themselves for what happened even if it was not their fault. It is difficult to stop blaming oneself.

> "I still have trouble blaming myself for everything he did to me. And I'm really trying to get past it all. It is a really hard thing being told for many years that you'll never be good enough, that you are trash. All these horrible things."

> "I actually sometimes will get mad at myself…Why didn't I understand this stuff? Why didn't I understand what was happening, or why didn't I say something?"

Poor Self-Concept and Trust

Sexual violence impacts a person's self-concept and ability to feel comfortable around other people. One survivor expressed, "I had times where I was, like, Do I matter?" For another individual:

> "I still feel like in a way I'm damaged. Because I feel like I have an invisible sign on my head that says, 'Damaged Goods'…Unfortunately, it (the abuse) did have something to do with it, but I can't put my finger on how or to what degree it's affecting [my ability to have another relationship with a woman], you know."

Abuse affects friendships, intimate relationships, and family relationships. It can lead to doubting other people's intentions and the value of close relationships. Even with a survivor's own family, "All of a sudden, I'll be, like, 'do they really love me?' I don't know. Like, I'm scared."

Others shared:

> "I feel more uncomfortable when guys or males make compliments about me and how I look, and things like that...Because I think they're trying to [ask] me to possibly go out with them or make me do things that maybe I don't want to do, and I'll feel uncomfortable saying that to them."

> "I have a really weird connection with people to where, you know, I'm very, like, super glued attached. And, if I see a dis-attachment, then I'm like, 'I want to get out of that.'"

During and after an abusive relationship, it can be difficult to trust other people again, including those who may be of benefit. One survivor expressed, "Now I'm kind of not comfortable any time now...Even, like, a doctor appointment. I'm like - I don't even know who to trust anymore."

Survivors also become protective of their loved ones. As a victim of sexual violence,

> "I'm someone who's very protective of who my son is around...I want to watch him because I don't want the same thing to happen to him."

Reporting Sexual Violence

Reporting the abuse took courage and the results were not always positive. When it was reported, the responses from family, law enforcement, and school personnel were mostly not helpful or supportive. It took one or more individuals to advocate for or protect the victim. Some survivors did not tell their family or those close to them about what happened. For some individuals, it took a long time, even years before they were able to talk about the abuse.

After the report of sexual violence was made, survivors continued to experience trauma from the incident(s) and also during the reporting process. One person reported that after filing a police report, “Nothing ever came of it.” For another person, the outcome was more positive. The student made a report to the police and the resource office at the school “looked out for” the high school student and she was able to receive help from the counselors. School personnel may not identify the signs of sexual violence but,

> “The minute that I said that I was being raped by my stepdad, everything stopped. All of a sudden, my teachers figured stuff out that they should have been figuring out ages ago because I had already been showing signs apparently, but nobody was putting two and two together.”

For other survivors, telling family about the abuse can bring mixed responses. It “took a while” for one survivor to report the abuse to her mother. Her mother’s response was, “You sure you’re not making it up?” The experience for another person was very different:

> “Just recently, I came out to my family. They didn’t know the full extent of it. Once they found out that I was being beaten and raped, and all this other stuff, that’s when they decided, I need help because I get panic attacks and horrible depression…And I apologized to my parents a lot saying, ‘I’m so sorry I didn’t tell you guys sooner. I’m so sorry.’ They have forgiven me, which is good. But it really is hard.”

Not Being Heard and Believed

Survivors were questioned about their responsibility in what happened, and whether they were telling the truth. The following experiences show the hurtful impact of behaviors and words from individuals in our legal and health care systems. It took courage to report the abuse and yet victims faced ongoing challenges.

Unfortunately, one survivor was told by the physician:

> "That's not rape because you were too scared to say no…You're giving him a cruel term when you're too scared to say no." Survivor was indeed afraid. She told her doctors the story about how she was raped. Then "he changed his mind and said, 'Now that you're actually clarifying how it happened, then yes, that is considered rape.' So now he believes me that it was rape."

The contact with the prosecutor in the legal case had lasting effects on the survivor:

> "After I had reported him as my abuser, it had already been, I think, a month after my 18th birthday, so they didn't count it. I literally had the prosecutor basically tell me it was my fault and, had I actually been raped, I should've said something before 18. So, they didn't really count what I said even though all the signs showed."

Words That Hurt

Survivors want the community to know that people with I/DD and autism may not be able to verbalize that they have been abused. Care providers must pay attention to non-verbal communication, changes in behaviors, and physical signs of abuse. Care providers need to accurately document signs of abuse when they encounter them. It is also necessary to understand that comments made, even if well-intentioned, can be hurtful to survivors. Survivors in this study found the following comments hurtful:

- Why didn't you leave sooner?
- Why didn't you just leave?
- Why did you allow him to do that?

Support from Family, Friends, and Professionals

Formal and Informal Supports

Counseling services were not easy to access. Counselors were difficult to find, and services were not provided in a timely fashion. Survivors did not receive counseling for reasons such as program eligibility and insurance coverage. Individuals were able to find support from their church and school.

One individual had to wait 5 ½ months to get an appointment with a counselor at a community mental health agency. Another survivor contacted a domestic violence agency and "They turned me away because my abuse happened five years ago."

One individual wanted other survivors to know that support can come from family members, support staff, work staff, and a best friend.

> "I want them (i.e., survivors) to know that they have family, friends that love them. It may not seem like it, but they're your biggest support system."

Strength and Healing

Telling one's story is often part of the healing process. Survivors of sexual violence talked about what lies ahead for them. Sharing their lived experiences is one way to help other survivors find strength and to continue their own healing. Survivors shared the following words:

> It's possible to get out. You just have to have the strength to get out.
>
> It's 16 years later and I'm still here and stronger than ever. So that's why I say I feel like I can walk through fire.
>
> I can honestly tell you, though, my life is more genuine now than it was 12 years ago.

Part Two:

Families Share Their Stories

The families that shared their stories are strong and resilient. Their stories tell us about the impact of sexual violence on individuals, families, and communities. The message they share is that sexual abuse can still occur despite parents' attempts to ensure the safety of their daughter or son.

Sexual Violence Can Happen to Anyone

The parents who participated in this project were active members in the disability community. They were knowledgeable about community supports, and how the education and service systems function. Despite their knowledge and experience, their families were still victimized and traumatized by their experiences with sexual violence. They heard from "several adults on the spectrum that their sexual abuse had happened at the schools." One family was "very guarded with his care, and we also homeschooled because we were concerned that the schools were actually not that safe." There is "silence around all the opportunity for things to go wrong with our teens and adults because we don't feel comfortable sharing like we had in the past" (when their child was younger).

Awareness about Sexual Violence

One parent felt that the community is aware of the prevalence and occurrence of sexual violence but is unhappy with how it is addressed:

> I think they know very well that it is alive and well. I think the way that it is handled is less than professional. I certainly see that once it has occurred, rather than diverting any type of behavior - I think we tend to put out the fire after the event. And I see that from personal experience, throughout the course of the years with the DD community. And it's very frightening that's the level of which it is occurring.

One parent was particularly concerned about the lack of support for college students:

> "I know whose kids went to college ended up dropping out for a little while, having a nervous breakdown because there's no social and emotional support. Educationally, they can do it...but the social-emotional stuff, he needed help, and there was no help for that."

> "And I thought I was on my game, but apparently, I wasn't. But I got forewarning. Most people don't even get forewarning. So, I think that's hard too. I know we see all this abuse in the group homes, and it's horrible, but I think there's just as much abuse with the high functioning kiddos."

> "It's just that nobody can talk about it. And that's scary too."

Paying Attention to Inappropriate Behaviors

Sexually inappropriate behavior in persons with I/DD may not be addressed as soon as it occurs. This includes comments that are sexually suggestive as well as inappropriate physical contact. Examples provided by the parents in the study included comments made by young women towards neurotypical and non-neurotypical men. For example, "One young lady refers to a bus driver - the Sun Van bus driver as sexy legs. I think that's happened on multiple occasions. That wasn't shut down immediately."

One parent wanted to know more about how an incident was handled by the staff supervising a social dance. She felt their response was not adequate and did not address the problem:

> "There was a young man that actually came up behind my daughter and we're talking through the dance...and he came up behind my daughter kissing her on the neck and my daughter did go to one of the staff members there. And of course, they will not directly tell you what and how it was handled, but most of the time they will ask the individual that they can't participate for X amount of days or X amount of months."

Perpetrators

Perpetrators can be male or female, individuals with and without disabilities, new and old acquaintances, and trusted individuals. Perpetrators can be extremely skilled at manipulating their victims.

Perpetrators in these cases were individuals known to either their child, parent, or both. Three families shared their experiences with perpetrators and the impact on their child.

One perpetrator contacted a parent's daughter through Facebook Messenger. This young woman was groomed and manipulated by an older male who told her that she was not brave enough to allow him to take pictures of her unclothed body. Her daughter became "very secretive" and their relationship became very strained. The case is being investigated. The victim's mother vows that she is "going to be the squeaky wheel" in order to protect her daughter.

The school failed to protect a high school student who was bullied. The victim was laughed at, made fun of, and "some really horrible things" were said to him in front of his classroom. The classroom door was "wide open," allowing other students to observe the victim's abuse. A male student also made fun of how the victim was using a urinal in the restroom. He was videotaped while in the restroom.

A college student was living on campus and abused by another student who "targeted him and purposely messed with him and destroyed him. It was like a cult. It was a very tiny little cult."

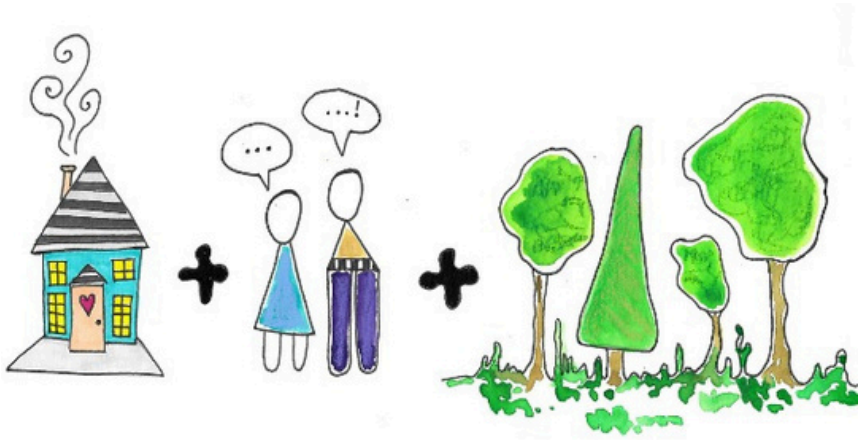
Perpetrators identify their victim and begin to control that individual by emotionally breaking them down. Some very painful experiences were shared:

> "It was a matter of him gaining my daughter's confidence. All of a sudden, I became the evil person. He tried to turn my daughter against me. He tried to build a wedge in between myself and she. Building himself up as this very intellectual individual. And I kept telling my daughter he is not a knight in shining armor."

> "He (son) was a completely non-functional person. He would talk, and it was like, I think his friend called it word salad. Like it wouldn't even make sense… She had him sleeping from 4 a.m. to 5 p.m. He was only eating one meal a day. Like, all of this was done so that she could break him down and manipulate him. So, then we had to sort of put it back together."

One parent wanted us to know this important point:

> "But a lot of them, the reason they (perpetrator) get off so easily and the reason that they don't even get prosecuted, is because you have these really convincing, charming, charismatic, loving, attentive, doting figures that, in reality, manipulate as much as they possibly can to where they can get away with it when they're finished."



The Impact on Family Relationships

Perpetrators will isolate their victims from family and existing support systems. This enables them to control their victims more fully. One family shared how the perpetrator mentally affected her daughter by putting a wedge between them – “My daughter and I used to be extremely close.”

Perpetrators, both male and female, will convince their victim that they should not lean on family.

> “So, she (perpetrator) convinced him that he really shouldn’t lean on us, that he could lean on her. That was kind of the first step. Then I think she had sex with him, because she knew that could manipulate him. And then she used a couple other friends. So, she’s manipulated I think three or four people with autism into this little cult.”

Changes in Victim’s Behaviors

It can be difficult for parents to know about everything that is happening in their children’s lives at all times. Even through their adulthood, parents felt it was important to maintain good communication. Parents stressed the importance of being alert to any significant changes in behavior that might indicate that an individual with I/DD is being victimized.

> “I think it's a matter of knowing what your children are doing. I think it's about knowing your child. When you notice things that don't seem quite right, they become a little more secretive. That's when it's time to start picking up. You know, there's ways of getting things out of people without looking controlling...They're going to show some signs of that because of their heightened senses and their inability to handle some things that occur like this because they will react to it and it's a matter of just digging, being aware, watching their surroundings, watching your surroundings, communicating, digging.”

Sex Education

The role of sex education was brought up during the interviews with parents. They shared their perspectives about the role that sex education plays in addressing sexual violence. Sex education was viewed as “one small strategy” and one parent worried that “people think that’s the strategy.” Another concern shared was that “I do think sex education is really important, but I worry about, who’s going to decide what that looks like. Making sure that we’re being careful about how we do that.”

Another perspective was that sex education needs to start early and be discussed by qualified individuals:

> “It needs to start in high school, maybe even junior high depending upon the level of function. I think the biggest thing is start early, according to their understanding level. But again, I think it's something that the schools need to do. I think they owe that to the children. I know some parents don't want their children hearing about certain things, but you can't sweep it under the carpet. I know that there's a lot of families that don't want Planned Parenthood stepping into that position, but if you as a parent don't step into that position, you need to find somebody who is equally qualified to address that outside of the parental role.”

Counselors and a Team of Experts

Access to counseling and therapy is difficult, especially when an agency feels they are unable to help someone. Through perseverance, a family was able to find a skilled counselor through word of mouth. For some, it takes a team of professionals to help a survivor and the family. One family had a negative experience with counseling because "He (former counselor) wasn't able to help us, so they just shut us off because (son) was so low verbal when he was like 12 or 13." Fortunately, they later found a "phenomenal lady that he (son) sees on Fridays." For another family, "I arranged for him to see a neurologist, a sleep doctor, naturopath, a regular doctor because he was a train wreck."

The Benefits of Counseling

Survivors of sexual violence experience different types and levels of trauma They benefit from counseling when you can find a good fit between the individual and professional. Finding the right therapist may take time and they are often found through community contacts and friends. The healing journey can bring about some very positive changes:

> "He's starting to talk about feelings, and he has acknowledged that he has been bullied before. He is starting to dig a little bit deeper, but it was interesting because so many things happened at one time and because he's so low verbal. But he wants to talk more, and so we're going slow with this therapist. But he's starting - we started with just basic feelings. He's actually starting to independently bring up the feelings to her - so we're getting somewhere."

> "He is doing beautifully. So, at one point, he was self-abusing himself so badly. He ripped out so much hair out of his head, that he was able to see that he wasn't competent."

The Legal System

The decision to press or not press charges is extremely difficult. The legal system is challenging to navigate, and a victim's credibility is often questioned. Families who pressed charges shared the following suggestions when interacting with the legal system. The legal process can be long, "lonely and scary." Survivors and families need a support system. One family "had a lotta people that supported and helped, and so it scares me for people that don't have that."

One parent had the following recommendation:

> "I highly recommend to anybody that does it to use your court advocate. I was so grateful for that person because they really were able to access questions and answers. Knowing that you have the ability to have that advocate dig deeper into areas and ask questions to lawyers. They're your person to get information from the other sources."

One family decided not to press charges. She was told that,

> "He wouldn't be taken seriously. He wouldn't be believed. He would be destroyed on the stand. He just wouldn't be able to make it through the whole thing and be a functional human being."

Since the legal system does not always work for the survivors, the only other option is to work on risk reduction – "we got to figure out how to prevent it better."

Part Three:

Professionals Share Their Experiences About Sexual Violence

> It's important that people know what is in their (i.e., survivor of sexual abuse) history, because what is sometimes labeled as aberrant behavior is really a direct result of a trauma they experienced that we may never know about.
>
> But we always get stuck on this sort of...the *"What can we do?"*

Fifteen professionals in Arizona talked about their experiences supporting individuals with intellectual and developmental disabilities in various settings. During their careers, they worked in or with contracted provider agencies, group homes, day programs, vocational rehabilitation, juvenile detention, county programs, Department of Child Safety, Adult Protective Services, Arizona Training Program Tucson (ATPT), psychiatric residential treatment, and the Arizona Department of Economic Security Division of Developmental Disabilities. They held positions as a direct support provider, program manager/director, supervisor, case worker, case aide, social worker, counselor, crisis staff, quality assurance staff, personal caregiver, and attorney. These professionals provided important historical and current perspectives on Arizona's programs and systems. Their experience in the disability field ranged from four years to 43 years at the time of their interview. The conversations lasted from 60 to 90 minutes.

Awareness About Sexual Violence

Professionals were keenly aware that sexual violence against individuals with I/DD exists and is underreported. They experienced the lack of awareness among the community and families. Program staff were concerned that parents and guardians would be upset if they included discussions about sexual violence in their programs. This is a misconception that can hinder addressing this problem.

> "I think there's fear of well, if we talk about this, is XYZ going to happen or are we going to upset the parents and guardians that we work with?"

Professionals stressed that sexual violence could happen in a family home, group home, or other settings and there is increased vulnerability when

> "No one in there is laying eyes on the member and they have no other involvement in programs. There are a lot of things that could be happening that we don't know about."

For individuals who were not receiving support through systems like the Division of Developmental Disabilities, awareness and reporting of sexual violence will depend on the "eyes and ears of people in the community." At the same time, "individuals who live with family and are not receiving any services beyond case management or support coordination can still be vulnerable and be victims of abuse."

In addition to the lack of awareness about the prevalence of sexual violence, there was a concern that direct support caregivers who worked in group homes did not understand their responsibility as mandated reporters and what it meant to comply with the law. One professional was surprised that there appeared to be underreporting of incident reports from home-based service providers because the person with I/DD can be in a very vulnerable position. Incident reports occasionally came from "work programs, landscaping crews, and janitorial crews."

Reporting of Sexual Violence

There are a variety of reasons why sexual violence is not reported. Persons with I/DD may find it difficult or traumatic to report their perpetrators because nobody was around to witness the event. Victims may wait years or until they are much older to report their abuse. Grandparents talked about "what happened to me when I was little." Victims did not report their abuse because they did not know who to turn to or how to report it. Some children assumed that adults in their lives are aware they are being abused. Professionals may have had suspicions but felt that the victim was not ready to talk about it.

When victims did report, there were triggers and circumstances that allowed individuals to share their stories. Victims needed a safe place to talk about what happened to them. When there is a safe place or person, there may be triggers like events, social situations, or changes in one's life that make it possible to talk about their experiences.

People who support individuals with I/DD must be able to pick up on the words, behaviors, social cues, that tell us something may be wrong, and that they are ready to talk about it.

> "We were in a small social group. We would chat...and so that's when abuse came to light."

> "Kids have this image that adults know (about the abuse). So, they're contributing to it. So, why would you tell your mom if you think she already knows?"

In order to create safe spaces to talk about the abuse, professionals felt that it is important to spend time with the individuals in order to get to know them.

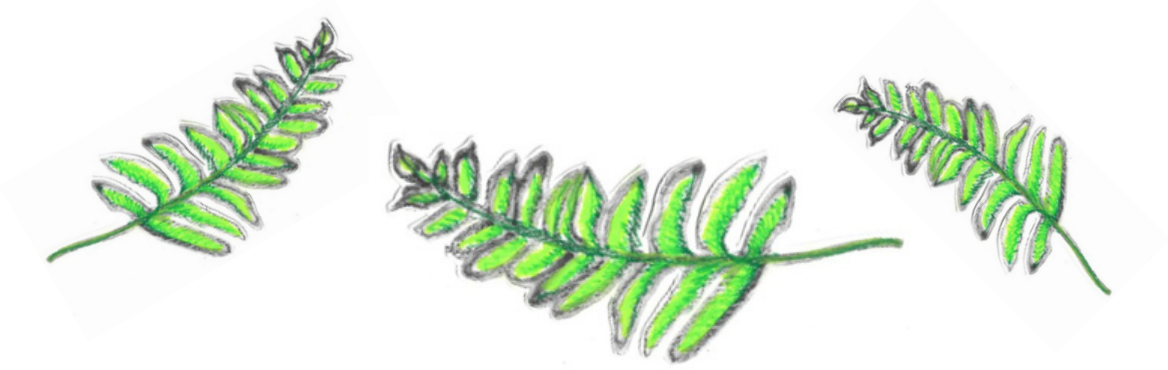
> "We don't spend enough time, like I did in the early years of my career, analyzing behavior that could be a direct result of a traumatic experience."

Individuals who were ready and shared their experiences wanted their information to be used to advocate for more resources and to increase conversations around this topic for people with I/DD.

Victims of Sexual Violence

The victims of sexual violence were abused by a partner, family member, person in their life, and friends. Perpetrators were individuals that the person knew. Each professional recalled cases involving persons with I/DD who may have also had a dual diagnosis (e.g., I/DD and a mental health diagnosis). Each of the following cases are extremely disturbing. Not all of the cases are included in this report. The victims experienced:

- Significant abuse and rape starting at a very young age when the parent invited people over to have sex with their child.
- Severe trauma while in a psychiatric hospital where this person was taken advantage of “so seriously that it just damaged her.”
- Stalking by a former partner who kept coming to the house.
- Rape at a young age by someone who groomed this person and who “didn’t have places that they could go to get services or understand truly the extent of what was happening to them.”
- A traumatic brain injury that resulted in difficulty learning from previous mistakes and engaging in risky behaviors.
- Abuse by his Cub Scout leader and was not believed by the family.
- Ongoing abuse by a parent who targeted both the daughters and sons.
- Having a grandfather who tried to break into their home to abuse the children.
- While in elementary school, being taken to places by an uncle who regularly abused the child.



Perpetrators

Perpetrators took advantage of the fact that the victims had a cognitive disability. They knew how to identify and isolate individuals and planned opportunities to be alone with their victims. They groomed individuals over several months and years. Perpetrators would also purposely develop relationships with someone to gain access to their children. The COVID-19 pandemic increased opportunities to further isolate individuals with I/DD. Professionals reported that perpetrators did the following:

- Took a woman on walks, isolating her from the group and others in the home.
- Spent time alone with the individual while taking her to appointments or when picking up her medications.
- Told the victim that he "really liked her like a girlfriend."
- Dropped a person off last during transport in order to have time alone.

Impact of Sexual Violence

Survivors continue to struggle and experience life-long psychological effects from their abuse. Some individuals become abusers themselves if they think "I'm not that unusual" because "they don't realize that this isn't a normal thing that happens to children." It can also impact a person's relationship with intimate partners. Family members may blame the victim for breaking up the family or sending someone to prison.

> "I know that it's still something that, you know, she thinks about daily because she'll talk about it daily and it is incredibly traumatizing...she has self-injurious behavior that she really is unable to overcome."

Victims can sometimes put themselves in dangerous situations or react to the abuse by engaging in risky behaviors. For example, "I mean she put herself out online and ended up with some guys and exactly fulfilled the prophecy the staff said that she would."

The effects of sexual abuse may manifest behaviorally. This can include difficulties with maintaining socially appropriate boundaries and taking responsibility for one's actions. These behaviors can significantly limit an individual's ability to participate fully in society.

The impact of years of trauma manifests itself in a person's ability to be successful "not only just in employment but in life...they've burned out their family, they don't have any support system, and it's sad."

For some individuals it is difficult to leave the environment where the abuse was taking place and "some don't want to leave or go" because they don't have any other support system. They have to get food and shelter on their own and "you're either on the streets, where you're going to get abused, or you're at home, where the person may abuse you so it's really hard."

Individuals with I/DD who depend on caregivers for personal care have difficulty with trust if they have been violated in the past. They may be more comfortable receiving care from one gender based on what happened in their past. One hired caregiver explained that,

> "He's been violated. His integrity has been violated; he's been damaged. I can only imagine that. You don't look at many people the same way after that."

Sometimes a victim's need for love and intimacy may lead them to unknowingly enter into an abusive relationship.

> "You know, he will describe it this way himself, that he had been looking for love in a lot of the wrong places or, you know, wrong things have been inflicted upon him."

Investigating Cases of Sexual Violence

Allegations of sexual violence are investigated by different systems and groups. This process is intimidating, scary, and difficult for the victim and family. Quite often, people with I/DD are not believed when they report that they have been sexually abused. Staff may believe that the person was in some way responsible for what happened to them even if the individual needs help with decision making and has a guardian. Reports of sexual violence might not be taken seriously if "the consumer" (person receiving services), is viewed as a "complainer" or difficult. Labeling a person serves as a barrier during the reporting and investigation process.

In some cases, group homes do their own internal investigation. The assumptions and attitude of one group home were demonstrated in the following example.

> "But when we had reported [the abuse] to the group home, and they investigated, they had already completed their investigation and had emailed me saying that, it was our person who had been initiating the relationship, kind of instigating, the response from the staff member, and that, basically, we were lucky that that staff member wasn't going to make a complaint against our person."

The investigation process is very difficult on the victim. The community does not understand elements of the investigation process and the impact on the individual with I/DD.

> "The police were called. They came to interview her. She could not be examined vaginally at that point [because] she was so traumatized. She couldn't allow them to touch her at that point. She just couldn't so they just sent her home."

The collection of evidence and the availability of witnesses are critical to the investigative process. It is important to interview staff who interact regularly with the victim in order to provide the legal team with necessary and useful information.

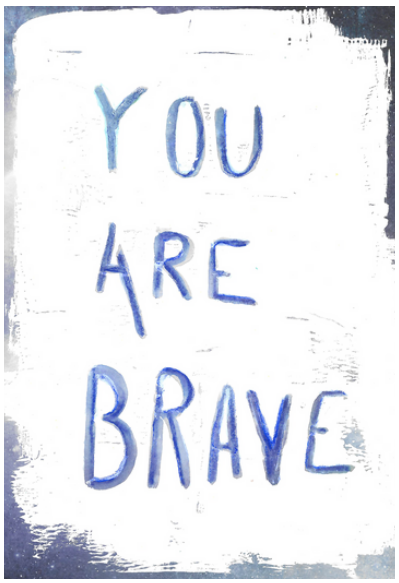
"We want to talk to the staff who sees that member every day. 'What are you noticing? What's the demeanor of the member? What's the wound look like?' A support coordinator's not going to be able to help us with that, but they are the facilitator of the team meetings where they do need to know this information and know the right questions to ask."

Support and Training

Both staff and victims need support. There was emphasis on the need for ongoing staff training and support because it can be difficult to hear the stories and support individuals throughout their experiences. For victims, having that one person who really cares and listens can make a big difference. This is the same for staff and families.

"It was heartbreaking to have experienced this with her. To recognize how ill-equipped she was, and of course she was. How little support there was. And there certainly was not, under the circumstance, there was not a safety net for her. And that part was really upsetting."

"I've been involved with people who have reported sexual abuse and then haven't been believed or were doubted about it. I would only hope there would be some enlightenment in the community to never disbelieve somebody – you always got to look into it."



Staff turnover was frequently shared in the interviews. Many of the direct care staff are paid minimum wage for a job where they are "dealing with real people and real people's issues and some people that are really hard to deal with." Staff may be working at their first job and don't get the support or training that they need to do an important job.

Several professionals felt that training on how to support people with I/DD is "often woefully inadequate, potentially putting consumers and others at risk for being harmed both physically and emotionally." Individuals may be well-intentioned but don't have the experience or the skills to know what to do.

The need for more quality training for staff and caregivers was frequently mentioned. Individuals who were employed by the Division of Developmental Disabilities at one point in their careers felt that "we need training from subject-matter experts" who have done direct care or "fully appreciate just how vulnerable everybody is in some of these situations." Subject matter experts can address how a person may not be able to be a "good self-advocate or articulate or speak well about how they think they might have been victimized."

Staff who work directly with persons with I/DD may begin working with members before they receive any training. Staff training was described as "piecemeal, occurring on-the-job." Professionals felt that staff "need to receive training on ways that people with I/DD and autism communicate. This is important because changes in behavior may be a sign that a person has been sexually abused."

Professionals identified topics that should be taught and discussed in trainings. During the orientation for new staff, topics should include more than information on how to fill out required forms. Trainings that address Article 9 and consumer rights should also include, "what does that really mean and look like?"

The amount and type of training staff received was dependent on staff roles. For example, Quality Assurance staff received specific and more in-depth training.

The discussions about training needs were personal reflections of what professionals experienced. State systems and agencies appear to be addressing these issues but there is always room for improvement.

Training programs may be different now but one professional shared that,

> "When I used to train staff, we didn't even talk about the most fundamental kinds of contact that are respectful. And I shudder to think about how people are assisted in their home. They (i.e., members) don't know if they're being victimized or not; it's what they know."

Sex Education

Professionals reported that family members and individuals with I/DD had questions about sex education. They wanted to know who was providing this education and the content of the class or curriculum. Individuals were interested in understanding what behaviors were appropriate in private versus public spaces, consent, how to respect boundaries with different people, and pregnancy related topics. Individuals with I/DD were always eager to learn more.

Systemic Concerns

Individuals with I/DD may not be adequately served by the systems designed to ensure their safety and welfare. People who perpetrate acts of sexual violence are often not charged due to difficulty in verifying victims' reports. Staff may be terminated from the agencies that employ them, but nothing prevents them from seeking a similar position at a different agency. The police who investigate an alleged attack or assault identify the people who were involved, but each person interviewed may have a different story. The challenge is that

> "The individual who was attacked, assaulted, accosted is not a good self-reporter – is not able to say 'This person touched me here' – and so we are not getting a good report. In that case, oftentimes, those two or three people would be released from employment by that agency that they work for, but there would be nothing in the system that could stop any of them from getting a job someplace else to provide services for vulnerable people because nobody had been convicted."

Leadership, budgets, and priorities within organizations and state systems can change. New management can require that different information be documented in their incident

tracking system (minor and serious incidents, like sexual abuse). This can impact staff time, program priorities, and outcomes for people with I/DD. The data collected may help the system but not the consumers of services and supports.

Historically, when budget cuts were made, “the first thing that was cut were grief counselors, counselors who would address the physical abuse and any kind of violence against one of the victims. All of those positions were cut, and in fact, that's when we started to see the disintegration of our program review committees and human rights committees.”

The big concern was where energies and money should be directed? What is being tracked, what are the priorities, what impact does it have on current staffing and time, and who benefits. Do the changes that management and leadership make improve the safety of the people the organization is supposed to protect and support?

Behavioral Health Supports

Professionals identified the lack of behavioral health resources for survivors of sexual violence. The barriers to obtaining timely counseling services were insurance coverage, long wait times, difficulty accessing existing programs, or a lack of knowledge about what is available and where to find this information. Sometimes, the community psychiatric and counseling services are provided by different agencies, and they don’t work together. If one system is not a good fit for an individual, they have to start all over. One person found a counseling agency for the victim by “literally Googling.”

For another victim, the agency that provided psychiatric services (i.e., medication) for the victim’s mental illness would not see her for counseling because she had started with an agency located online and this was seen as “double-dipping.”

Referrals to behavioral health were made but not all counselors had the expertise in the field of intellectual and developmental disabilities. Also, if someone was enrolled with behavioral health, it was assumed that everything would be taken care of. There was a concern that the behavioral health plan was “not getting at the problem.” There was a perceived lack of coordination and communication among different teams that were supporting the individual with I/DD.

Behavioral health services and providers changed over time, and it became difficult to know what supports were available.

> "I would like to see that we can feel more confident that there's less victimization, that we have avenues for support of people who have been victimized. Not just a referral to behavioral health hoping that they'll have a counseling session. Some genuine support groups of, you know, who to go to for help. I honestly could not tell you in the later end of my career what the best resources were. There was a time when I could, but in recent years all of those systems that were in place have gone away."

Counseling services were seen as not available in comfortable and convenient settings. One professional wanted to see counseling brought to the school site where "kids get counseling for various issues or in the school that they're used to." The high turnover rate of behavioral health case managers and therapists was seen as disruptive to a victim's ability to receive quality therapeutic services. Individuals would "have to repeat their life stories over and over again, and who wants to tell that over and over again?" Professionals frequently felt that victims did not get the supports they needed.

Workforce

Professionals shared their concerns about workforce issues. Staff were not around long enough to get to know the individual and to understand that they are "telling us they're being victimized through their paraverbal or their body language." There were concerns that staff are not asking the right questions when they notice sudden and dramatic changes in a person's demeanor or behaviors.

> "It is important to ask each other if we are asking the right questions. When did we notice that? Do we have any data to support that on this night the member quit wanting to eat dinner with the housemates?"

Many individuals with I/DD are not able to develop trusting relationships with their behavioral health case manager, due to high turnover rate. This can make reporting incidents of abuse and receiving timely support services difficult for consumers.

> "And as a VR counselor, sometimes you were probably the person that they knew the best because, as you know, case managers at behavioral health were changing, you know, every other month practically."

Staffing

Staff can get terminated from one agency and hired by another quickly. Until a person is prosecuted for a crime, they can get hired elsewhere and "when they do the reference checks, you will probably know how there isn't much you can tell them or ask the previous employer." One barrier and safety concern for quality assurance purposes is that staff can move from one agency to the other and "many of them work for three agencies at the same time."

Staffing in residential settings during the overnight shift was a concern. The best-case scenario would be to have a minimum of two staff members present because "It minimizes the likelihood that impropriety could occur." Even if two staff members don't need to be awake at night there's a protection there to have two staffers present. If multiple staff in a setting is not possible, "there should be more opportunities for unannounced drop-in visits on the overnight shift or the day shift."

Health Care and the Impact of COVID-19

During COVID-19, it was very difficult for victims to receive timely health services and support. During the pandemic, one victim went to the hospital and the "trauma culminated there." The individual waited 12 hours to be seen and had to get a COVID test before she was examined. That did not occur until very late in the day. The pandemic was a very difficult period for victims, families, staff, and health care providers. The hospital did not have the process in place to give this type of situation high priority. One can only wonder what the outcome would have been if the individual was seen as soon as she arrived at the hospital.

> "She may have been more willing or more able to stand the physical examination. So, she wasn't able, by midnight, when the nurses actually came down to do that type of examination; she had been there all day. The medications were not given so, she was not able to stand anybody touching her and refused the exam."

The Legal System

Professionals familiar with the reporting and legal system made it clear that the process from beginning to end is difficult and prosecution success depends on several factors. For victims, the decision to press charges required guidance because it is not a supportive system. The prosecutor of the crime "might not feel that they have enough information to actually move it forward and present it to the court." For example, if a report is made to Adult Protective Services, the individual with I/DD will need someone "representing them (victim) that can help the prosecutor with pursuing as much evidence as possible."

It is necessary for judges who work in the area of law that involves sexual violence and abuse against persons with I/DD to "receive specialized training to also understand the capacities of adults with developmental disabilities and that, just being high functioning doesn't equal sufficient capacity for consent." One concern was how a judge might view a person's capacity and how they interpret the definition of high functioning. Short interactions with individuals with I/DD may not provide an accurate assessment of how an individual may respond in different situations.

A scenario might look like this –

> "If the disabled adult does not have a guardian who is savvy enough to talk about these things for the prosecutor, it becomes developing a strategy with the prosecutor on how to present your evidence. If the developmentally disabled adult is left on their own to have to deal with this, that would be another reason why, even if it goes to court, the outcome of actually having the person charged might not happen."

Part Four:

The Community Responds

An online survey was administered in 2022 by the research team to provide the community with an opportunity to share their concerns and recommendations on how to address the prevalence of sexual violence. The questions explored awareness, education and training, incidents and trauma related behaviors, and recommendations to address this problem. The survey link was disseminated through the Sonoran Center for Excellence in Disabilities listserv and website, disability organizations, and the Arizona Developmental Disabilities Planning Council website.

A total of 40 individuals accessed the survey from January to August. Of the 40, seven individuals did not complete the survey, leaving a total of 33 complete surveys. Responses came from Arizona, California, Delaware, Georgia, Montana, and South Dakota. The analysis for this report included 24 adults who lived in Arizona. The Arizona counties and number of individuals from each county were Apache (3), Cochise (3), Coconino (2), Gila (1), Graham (1), Greenlee (1), La Paz (1), Maricopa (7), Navajo (1), Pima (2), Pinal, (1), missing data (1). Individuals confirmed that they were 18 years and older and their own guardian (required response).

Participant Demographics

Three survey respondents identified as a person with a disability (deaf with hidden disabilities, I/DD) and twenty-one as a person without a disability. Thirteen individuals were family members of someone with an I/DD. The participants ranged in age from 22 to 53 years old. Individuals identified their race and ethnicity as Asian (2), Black or African American (4), Hispanic, Latinx/o/a or Chicano/a (3), Native American or Alaskan Native (4), White or European (12). Of the 24 individuals, 15 identified as female, seven as male, and two as non-binary. Individuals were interested in the issue of sexual violence for different reasons.

Why are you interested in the issue of sexual abuse and violence? (You may select more than one option).	**Frequency Counts**
My work involves supporting people with disabilities	17
I feel that sexual violence is a problem that is not being addressed	14
I know someone who experienced sexual abuse or violence	13
I feel I have something to contribute	7
I am a survivor of abuse (does not have to be sexual abuse)	5
Other	0

What best describes the focus of your agency or program? (can choose more than one response)	**Frequency Counts**
Adult Protective Services	3
Child Protective Services	3
State Agency for Developmental Disabilities Services	5
Education	4
Employment	2
Health Care	3
Mental Health	4
Rehabilitation	1
Other: Nonprofit	1

Individual roles or positions in these programs included: administrative support/management, caregiver, clinical trainer, case manager, faculty, HR manager, support coordinator, and therapist.

How would you describe the type of contact you have with persons with I/DD?	Frequency Counts (Percentage)
Ongoing direct contact	9 (38%)
Infrequent direct contact	5 (21%)
No direct contact	1 (4%)
Family member	1 (4%)
Missing response	8 (33%)

The following question and corresponding table show that only a small percentage of individuals felt that the general public and people in the disability field are aware of the prevalence of sexual violence. Overall, respondents generally agreed that they knew how to respond if they learned about and witnessed inappropriate sexual behaviors, and recognized the behaviors associated with trauma.

To what degree do you disagree or agree with the following statements?
(Frequency Counts/Percentage Rounded)

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
The general public is aware of the prevalence of sexual violence	1 (4%)	8 (33%)	6 (25%)	6 (25%)	3 (12%)
Persons who work in the disability field are aware of the prevalence of sexual violence	1 (4%)	5 (21%)	10(42%)	4 (17%)	4 (17%)
I know what to do if someone told me about an experience of nonconsensual sex or behaviors	0	3 (12%)	5 (21%)	12 (50%)	4 (17%)
I know what to do if I witnessed inappropriate sexual behaviors against another person	0	0	5 (21%)	12 (50%)	7 (29%)
I can recognize the behaviors that are associated with trauma as a result of sexual violence	0	2 (8%)	3 (12%)	11 (46%)	8 (33%)

If you were involved with a reported case of sexual violence against a person with I/DD, please describe what happened and if the survivor was able to receive appropriate support and treatment.

Respondents shared three cases of sexual violence and the outcomes for the victims. These cases revealed that: 1) victims who reported inappropriate sexual touch or personal care often were not believed, 2) there was a perceived lack of response by the Division of Developmental Disabilities, 3) people were not able to recognize the victim's behaviors that communicated signs of abuse, and 4) slow responses to the alleged abuse delayed necessary help and support for the victim.

- A consumer (person receiving services) reported that a van driver touched her inappropriately. Staff did not believe her and dismissed the claim. This impacted the consumer's ability to receive timely appropriate supports and treatment (i.e., psychological counseling, a medical exam, etc.).

- A male victim who required personal assistance, was touched inappropriately several times while receiving help with showering by a male care provider. The victim subsequently reported it to the agency that employed the care provider. He was told that the care provider was a great guy who did not receive any complaints from consumers during his more than 10 years of employment. The provider said the victim must be mistaken. The victim reported the incident to his DDD support coordinator. No action was taken by either DDD or the provider agency. The perpetrator continues to provide attendant care to people with disabilities.

- A family member of a person with I/DD reported that their child was unable to verbalize what was happening to them. Repeated anger outbursts and isolation around three staff members eventually indicated to family members that something was wrong. However, it took a while longer to discover the source of the problem. In the end, the victim received appropriate support and treatment, but it took much longer than it should have because family members did not initially recognize the behavioral signs of sexual abuse.

Where are you getting information about sexual abuse and violence?

Respondents found information about sexual abuse and violence from work and social settings, online searches, self-research, news, medical journals, trauma researchers, treatment providers, community service providers, Regional Behavioral Health Authorities, EMERGE Tucson, Abuse and Neglect Task Force, Arizona statutes, and trainings. One individual shared a variety of sources that included the International Society for Traumatic Stress Studies, International Society for the Study of Trauma and Dissociation, Trauma Institute International, International Trauma Training Institute, and Trauma Healing.org.

What would you like to know about sexual abuse and violence against persons with I/DD?

Respondents wanted more information about the following topics.

Information and Resources

- Resources that are available to members of the I/DD community and their caregivers/support systems/advocates regarding sexual abuse and violence.
- A flow chart that details how to report and address the needs of victims of sexual violence.
- More research on the topic.

Training and Education

- How to recognize the physical and emotional signs and behaviors of individuals with I/DD who have been sexually abused, especially those who are unable to communicate verbally or through gestures.
- How to verify the stories that persons with I/DD have shared about their abuse.

Trauma Care and Support

- How to help victims of sexual abuse cope with their trauma.
- How to support victims of sexual abuse following disclosure and subsequent investigations by law and state agencies.
- How to use therapy tools that are specifically targeted to treat sexual trauma in persons with I/DD.
- What therapeutic approaches to utilize while continuing to work with a survivor of sexual assault.

What do you think can be done to prevent sexual abuse and violence?

The recommendations focused on increasing awareness and communication, providing education and training, teaching about sexual relationships, providing family support, increasing staff and accountability, and making system changes.

Awareness and Support

- Create broadcast public service announcements to educate the general public about sexual abuse and violence against people with I/DD.
- Provide support to parents and caregivers and connect them with resources (including financial) to reduce their likelihood of taking out their stressors on persons with I/DD.
- Increase social supports and networks for victims and family members.
- Increase support to the vulnerable population, more protection and classes, workshops for those with I/DD on self-defense and right from wrong.

Education and Training

- Provide staff members, state agency personnel, and family members with more education and training on how to prevent and identify sexual abuse and violence.
- Provide training for people with I/DD about boundaries, body anatomy, good touch/bad touch in developmentally appropriate ways.
- Provide trainings frequently and reinforced by caregivers.
- Provide training on safe and consensual sexual activity recognizing that this may be a very difficult topic for members of the I/DD community and their families/caregivers.
- Provide mandatory annual trainings for staff, consumers, and families.
- Provide repetitive education and awareness, possibly quarterly since persons with I/DD struggle with memory or cognitive challenges.
- Provide training on how to verify concerns that are expressed by individuals with I/DD.
- Provide more state agency training for protective agencies.

System and Environment

- Increase accountability.
- Do not allow staff to work alone with consumers, rotate staff regularly to lessen the likelihood of looking the other way through familiarity, and utilize body cams/mics.
- Restructure state agencies, such as Adult Protective Services (APS) and Department of Child Safety (DCS), to address lack of follow up or involvement; increase the prevalence of consequences for perpetrators; increase state agency response time; provide greater law enforcement presence and awareness of how to respond to incidents of sexual abuse and violence against individuals with I/DD. There is still a lot of “pass the buck.”

Part Five:

Summary and Recommendations

This research project provided valuable insight into the lived experiences of sexual violence survivors, family members, and professional staff who support individuals with intellectual and developmental disabilities in Arizona. This section will highlight the research findings and provide recommendations on the next steps.

The recommendations may not be new, but it is a reminder that the community must remain engaged as we work towards sexual violence risk reduction, prevention, and healing. The recommendations will require financial resources, commitment, and time. Even if not fully attainable, it provides reminders of what is needed to address this issue. There are existing resources that can also be utilized. Our Arizona organizations and service providers are interested in working together to find solutions.

The findings and recommendations are categorized into three broad areas.

Area One:
Awareness and Support

Area Two:
Education and Training

Area Three:
Systems Services and Coordination

Area One: Awareness and Support

Findings:

- Sexual violence includes intimidation, threats, manipulation, physical and non-physical behaviors, and words.
- Non-consensual behaviors are prevalent, under-reported, and ignored.
- Sexual violence can start when the child is young and occur more than once.
- Victims may experience multiple abuses by different perpetrators.
- The impact of sexual violence on victims is devastating and long lasting.
- Individuals with I/DD may not fully understand what is happening to them.
- Having a trusted person in the individual's life is very important.
- Perpetrators can be anyone. They select their victims, manipulate behaviors and feelings, and isolate individuals from family/friends in order to control them.
- It may take years before a survivor feels ready to share what happened to them.
- Survivors feel they are not believed by family, friends, health care providers, staff, police, and legal professionals.
- Staff who provide direct or indirect support may be unsure about what to do when there are suspicions of sexual violence.
- Behavioral health and counseling services are often not accessible.
- Individuals with I/DD benefit from long-term therapy and counseling.
- Staff and care providers also need support and positive recognition for their work.

Recommendations:

1. Create a committee that develops and maintains a sexual violence awareness campaign. Members should include a diverse group of stakeholders and self-advocates. The campaign should target groups and settings such as: schools, health care, employers, day programs, disability organizations, and state systems. The purpose of this effort is to 1) educate the disability and non-disability community about the prevalence of sexual violence against persons with I/DD, 2) increase the identification of perpetrator behaviors, 3) empower victims to report abuse and non-consensual behaviors, and 4) create a culture of transparency among service providers and systems that support the I/DD community. These efforts create a sense of community and communicates to victims that their lived experiences will be listened to and believed.
2. Create an inventory of existing resources that can be adapted for specific audiences. One example is how to talk about sexual abuse available at: https://childmind.org/article/talking-kids-sexual-abuse/
3. Increase awareness about adverse childhood experiences (ACEs). This discussion should occur in behavioral health meetings and consultations, staff training, and trauma assessments.
4. Collaborate with existing community groups to disseminate materials written in plain and clear language. For example, groups that focus on self-advocacy, peer support, family caregiving, and mental health.
5. Encourage and facilitate social interactions that create a sense of belonging among individuals with I/DD and their support systems.
6. Create opportunities for families to share ideas and receive support.
7. Establish in-person and online support groups that are facilitated by trauma informed professionals.
8. Provide opportunities to recognize staff or programs that have developed sexual violence risk reduction programs.

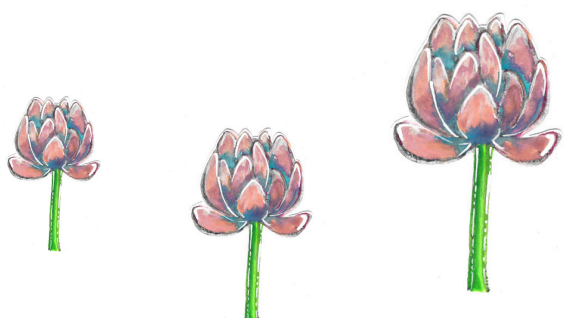
Area Two: Education and Training

Findings:

- Families are interested in developmentally appropriate trainings for their children.
- Healthy relationships and sex education are viewed as one strategy to prevent or reduce sexual violence.
- Building self-confidence and skills in self-advocacy are needed.
- Trainings that focus on perpetrator behaviors and manipulation are needed.
- Staff training should occur before working in direct care.
- Trainings on recognizing and understanding different forms of communication are needed for direct care professionals.

Recommendations:

1. Create opportunities for families to share their successes and how they addressed sensitive topics such as sex education.
2. Focus on peer to peer and family to family support groups and education.
3. Develop workshops on how to create materials using plain and clear language.
4. Engage health professionals from a variety of disciplines, self-advocates, families, and persons with lived experiences in the development of training materials.
5. Develop training curricula that are incremental in knowledge and skill development for different groups of participants.
6. Develop an inventory of trainings that are shared among different organizations.
7. Provide trainings at regular intervals and in formats for different learning styles.
8. Create opportunities to debrief after a training by a skilled facilitator.
9. Encourage organizations to reward employees for attending trainings and provide time to attend trainings.
10. Provide a certificate of training completion that serves to recognize staff accomplishments.
11. Work with academic programs and schools that train future behavioral health professionals in integrating sexual violence and I/DD in existing curriculum.
12. Conduct focus groups whose goal is to identify further training topics.
13. Provide trainings on the topics that were addressed in this report to stakeholder groups, individuals with I/DD, and families.



Training topics can include the following:

a. How to identify abusive behaviors using case examples.
b. What to do when you are being assaulted or abused.
c. Bullying: how to identify and how to respond.
d. Bystander training: how to develop the awareness, skills, and courage to intervene or interrupt in a potentially harmful situation.
e. Predators: how they identify and manipulate potential victims.
f. Social norms: how attitudes influence reporting of sexual violence.
g. How to create a support network when things go bad.
h. How to minimize risk for sexual violence and assault.
i. Mandatory reporting: Challenges and opportunities.
j. Building self-confidence and self-advocacy skills.
k. Identification and support for secondary and vicarious trauma.

Area Three: System Services and Coordination

Findings:

- Balancing individual privacy rights and the protection of individuals can be difficult.
- A lack of dependable funding for programs and systems leads to fragmentation and challenges with sustainability.
- There is a shortage of well-trained behavioral health counselors/therapists.
- Frequent staff turnover in small and large systems (i.e., support coordinators, mental health providers, direct care staff) makes it difficult for individuals with I/DD to establish trust in relationships.
- There is a perception that:
  - There is a lack of accountability for staff who mistreat individuals with I/DD.
  - There is a lack of communication and collaboration among state teams/programs.
  - Administration and leadership in state organizationsmay have priorities that do not align with what is in the best interest of the people they serve.
- Systems collect data that do not address the root cause of problems.
- The legal system does not have processes or guidelines that support people with I/DD.

Recommendations

1. Prioritize and secure state funding to address recommendations that focus on sexual violence risk reduction, professional training, system transparency, and accountability.
2. Create a state level office that sets priorities, reviews data, and oversees activities specific to sexual violence.
3. Examine staffing numbers in community residential settings.
4. Allow community members or an outside evaluator to review the data that are collected and how it is utilized.
5. Conduct regular root cause analysis to identify where and how systems can be improved
6. Share financial resources and expertise when collaborating on projects.
7. Encourage organizations that support individuals with I/DD to be more transparent.
8. Make it mandatory for administrators and leadership teams to attend trainings on sexual violence.
9. Engage the legal community in the discussion about sexual violence.
10. Identify strategies for better communication between behavioral health teams and other teams supporting individuals with I/DD.
11. Explore proactive monitoring practices to be implemented in residential settings, day programs, and other service provider programs. This may include unannounced site visits, meetings with parents and residents, published performance reports, and confidential check-in with direct support staff.
12. Continue to address workforce screening and hiring policies.