

JANUARY 2021

SEXUAL VIOLENCE AGAINST INDIVIDUALS  
WITH I/DD: A SUMMARY OF FINDINGS IN ARIZONA

# SUMMARY REPORT

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# Summary Report

## SEXUAL VIOLENCE AGAINST INDIVIDUALS WITH I/DD: A SUMMARY OF FINDINGS IN ARIZONA

# SUMMARY REPORT

**S**exual violence is a pervasive public health issue that disproportionately affects women, racial and ethnic minorities, and individuals with intellectual disabilities (Barger, Wacker, Macy, & Parish, 2009; Black et al., 2011). Current data by the Centers for Disease Control (CDC) indicate that about one out of three women experience some form of sexual violence during their lifetime—about twice the rate of men (Smith et al., 2017). Individuals with intellectual and developmental disabilities (I/DD) are at an even greater risk to become victims of sexual violence than individuals without disabilities. Bureau of Justice data indicate that the rate of rape and sexual assault against individuals with intellectual disabilities is more than seven times the rate of individuals without disabilities. Among women with intellectual disabilities the rate increases to about 12 times the rate of women without intellectual disabilities.

The severity, pervasiveness, and lasting consequences of sexual violence among individuals with I/DD raise questions about the current state of the nearly 110,000 individuals with I/DD estimated to live in the state of Arizona (Braddock, Hemp, Tanis, Wu, & Haffer, 2017). To answer these questions, the Arizona Developmental Disabilities Planning Council (ADDPC) commissioned a comprehensive **current state analysis** to (a) identify best practices in the research literature and (b) determine the extent to which the state of Arizona utilizes them in the areas of detection, reporting, tracking, monitoring, training, and prevention related to sexual violence/abuse among individuals with I/DD.

# METHODS

To address the current state and best practices, this research was completed using a concurrent triangulation design (Creswell, 2009) that brings **quantitative data** (i.e., day treatment and group home provider surveys) and **qualitative data** (i.e., interviews, focus groups, document review) alongside best practice recommendations found in the peer-reviewed literature to **highlight gaps** in the current system **and make recommendations** for improving the system related to the detection, reporting, tracking, monitoring, and prevention of, as well as training related to, sexual violence/abuse against individuals with I/DD.

# PRESENTATION OF FINDINGS

Due to the expansive nature of this research project, findings and recommendations are presented in two ways. First, this **summary report** provides a brief overview and synopsis of the work completed as well as a set of specific findings and recommendations from across all study strands. Second, a series of three standalone reports provide a **detailed account** of the methods, findings, and recommendations discerned from each strand of the research design. The following standalone reports can be accessed via the [ADDPC website](#):

- **State of the Research.** A comprehensive literature review that identifies available best practices associated with the detection, reporting, tracking, monitoring, and prevention of, as well as training related to, sexual violence/abuse against individuals with I/DD;
- **State of the Providers.** A detailed report of survey results by day treatment and group home providers across the state of Arizona related to key practices as identified in the *State of the Research* report;

- **Lived Experience.** A report that provides in-depth accounts of the experiences and perspectives of individuals with I/DD, their caregivers (i.e., family members, legal guardians), law enforcement officers, and Family Advocacy Center (FAC) representatives.

For more information related to the detection, reporting, monitoring, tracking, prevention, and training related to sexual violence/abuse against individuals with I/DD, please view the full reports found on the ADDPC website. Questions related to this project can be addressed to the [ADDPC](#) or directly to the research team at [info@improvementassurance.com](mailto:info@improvementassurance.com).

# DETECTION

## SUMMARY OF BEST PRACTICES

Defined as the act or process of identifying the risk for, or the presence of sexual violence/abuse against individuals with I/DD, detection is a broad research category that encompasses policies, procedures, tools, and practices designed to help assess a person's risk of being a victim of sexual violence/abuse and/or identify when someone has already been a victim of sexual violence/abuse. This category includes tools such as risk assessment and screeners as well as practices associated with the investigation of allegations of sexual violence/abuse. A comprehensive review of literature ( $n = 31$ ) identified several key themes:

- **Identification of Risk Factors**
- **Screening or Measurement**
- **Investigation of Allegations**

Research findings related to **risk factors** examined the personal characteristics and contextual characteristics that put a person at increased risk for experiencing sexual violence/abuse. The most well documented personal characteristic associated with risk is **disability status**. Individuals with disabilities are at significantly higher risk for experiencing sexual violence/abuse than their non-disabled peers. Risk is further

compounded when a person’s specific disability is an intellectual or developmental disability and/or if they have multiple disabilities. Additionally, age, gender, and behavior all play a role in risk as well. Researchers found that females, younger people, and those who display non-compliant and/or aggressive behavior are at increased risk for experiencing sexual violence/abuse (Kamavarapu et al., 2017).

Contextual characteristics of risk are further divided into three groups: (a) caregiver/parental, (b) staff, and (c) facility. **Table 1** lists specific characteristics that increase risk within each of these domains.

**Table 1.** *Contextual Characteristics of Increased Risk*

<b>CAREGIVER/PARENTAL</b>	<b>STAFF</b>	<b>FACILITY</b>
Interpersonal/domestic violence	Largely able, non-trained frontline staff	Lack of proactive reporting structure
Instability or changes in caregivers/parents		Unsupervised personal and/or medical care situations
Use of illegal drugs		Ineffective staff supervision
Use of homeless shelters		Lack of policies and procedures that address sexual violence/abuse
Low educational attainment		
Teen pregnancy		
Four or more children		
Receipt of child or income support		
Low socioeconomic status		
High levels of stress		

The high prevalence of sexual violence/abuse against individuals with I/DD “confirms the need for universal screening for abuse during every client contact in rehabilitation, health-care, and other professional settings” (Hassouneh-Phillips & Curry, 2002, p. 102). The current body of research points to a number of **screening or measurement** tools and methods that can be used to detect sexual violence/abuse.

Generally speaking, these tools and methods fall into two groups: (a) screeners/questionnaires; and (b) interviews.

For both options, the intent is to administer a set of questions that an individual with I/DD answers verbally, in writing, or using computer assistive technology. These questions are designed to encourage disclosure of sensitive information without waiting for an individual to self-report an instance of sexual violence/abuse. Details on the specific tools and methods can be found in the *State of the Research* report under the Detection section.

Finally, the current body of research makes a number of recommendations related to best practice during the **investigation of allegations** of sexual violence/abuse. The forensic interview remains the primary investigatory tool and ought to be modified based on the interviewees (a) age and developmental abilities, (b) cultural differences, (c) disabilities, and (d) trauma (Newlin et al., 2015). Specifically, there should be collaboration between the forensic interviewer and a disability specialist or another person with in-depth experience about disabilities and who has the necessary accommodations and modifications for purposes of communication. Further, this interview should sit within a larger investigation process that is legally sound and conducted by professionals with specific training for working with individuals with disabilities.

## FINDINGS

- \* **Risk awareness is high.** Across all subgroups of stakeholders included in interviews, focus groups, and surveys, over 85% self-reported familiarity with risk factors associated with sexual violence/abuse. Of the subgroups, caregivers and providers demonstrated the greatest knowledge of risk factors while law enforcement officers self-reported having little understanding of risk factors.
- \* **There is significant discrepancy between the reported policies/procedures for the use of risk assessment and screeners at day treatment programs and group homes and the lived experience reported by individuals/caregivers.** The majority (73%) of day treatment providers and group home providers (77%) agreed or strongly agreed that they had policies and procedures in place for determining risk using such tools as risk assessments at intake or periodic screening. However, none of the caregivers or individuals with I/DD who participated in interviews reported experiencing screening or risk assessment.

Further only 52% and 60% of day treatment and group home providers reported that their staffs have been trained on screening or measurement tools to determine risk or presence of sexual violence/abuse against individuals with I/DD. Across the two provider groups, survey respondents cited individualized service plans with details on risk and/or prevention of sexual violence/abuse strategies specific to the participant and risk assessment at intake as well as monthly policy reviews and same gender assignments (e.g. female providers work with female participants) as specific examples of strategies in use. While all of these strategies are valuable, many fall outside the definition of screening/risk assessment tools and policies. Similarly, many of these tools and strategies are solely staff administered. A combination of these two factors could be contributing to the discrepancy in that it is possible some individuals/caregivers are unaware of practices that are in place and that some providers are naming the purpose of existing practices as detection related when they are better aligned to other categories of safety efforts.

- \* **Too little is known about what NOT to do when an individual with I/DD is suspected to have experienced sexual violence/abuse.** When asked about staff trainings on the risks involved with asking individuals with I/DD about possible sexual violence/abuse, only 63% of day treatment providers strongly agreed or agreed that their staff have been trained. 66% of group home providers strongly agreed or agreed. These numbers indicate that roughly 30-40% of staff may be lacking critical information to refrain from questioning an individual with I/DD who may have experienced sexual violence/abuse. This information, especially when paired with caregiver reports that they (93%) will take action, even in the absence of procedural information if they were to suspect their loved one has experienced sexual violence/abuse, highlights a key system gap. In the event that a stakeholder who is not trained in proper forensic interviewing techniques with individuals with I/DD questions them about a possible sexual violence/abuse, they risk compromising the accuracy of the information provided and consequently the investigative process. Such action could have serious detrimental effects on the investigation, substantiation, and prosecution process.

- \* **The extent to which individuals with the appropriate, specialized training for investigating sexual violence/abuse against individuals with I/DD are utilized remains unclear.** Investigation-related documents were reviewed to discern the extent to which specific policies have been enacted requiring the use of disability specialists and specially trained forensic interviewers during the investigative process. Expectations stated in the submitted documents were limited to investigations involving children and spoke broadly to the expectation that departments have a “specialist” or a “specialized unit to investigate these violent crimes (Multidisciplinary Protocol for the Investigation of Child Abuse, 2015, p. 1).” Focus group interviews with law enforcement officers and Family Advocacy Centers did speak to the use of specialized techniques and specially trained staff when working with individuals with I/DD. Further, these individuals also spoke to the need to balance best practices with establishing policies that do not generate unintended consequences in the investigation process (e.g., restricting the ability to investigate in a timely manner due to staffing issues).



## RECOMMENDATIONS

Based on understanding of the current state and recommended best practice provided by the literature, the following recommendations have been formulated to support improving systems and conditions for individuals with I/DD in Arizona:

- ✓ Administer risk assessments for sexual violence/abuse in facilities that serve individuals with disabilities to determine risk level based on personal characteristics including age, gender, and disability type(s); and contextual characteristics of the parent/caregiver, staff, and facility. Adjust member care plans and staff practices based on individual risk assessments **[1.1]**
- ✓ Administer universal screening assessments in facilities that serve individuals with disabilities with options for audio computer-assisted self-interviews (ACASIs) **[1.2]**
- ✓ Train pediatricians and therapists, especially those who serve a large number of individuals with I/DD (ALTCS and ACHHHS eligible individuals with I/DD), on the use of screeners **[1.3]**

- ✓ Train forensic interviewers on techniques that consider the effects of age and developmental abilities; cultural differences; disabilities; and trauma [1.4]
- ✓ Ensure the availability of a disability specialist during forensics interviews [1.5]
- ✓ Ensure implementation of Abuse & Neglect Prevention Task Force Recommendation 16 (*“By 06/30/2020, DES should convene stakeholders to develop strategies on trainings related to protection against and disclosure of alleged abuse and neglect, including the Silver Alert program. Everyone to whom a vulnerable individual might disclose an alleged incident should be trained by employers or community-based organizations on what to say — and not to say — to avoid any conversations that might inadvertently interfere with substantiation and/or prosecution. The training should be tiered by role: vulnerable individuals, families/guardians, staff, facility administrators, and APS/law enforcement investigators. A wide range of training mechanisms should be employed, including the public awareness campaign recommended below as well as trainings offered by agencies, providers, and third-party entities” Abuse and Neglect Prevention Task Force, 2019, p. 11*) and 17 (*“All investigators should complete training on the specific special needs of individuals with intellectual and developmental disabilities (I/DD). By 10/1/2020, contracts should require that personnel who investigate alleged incidents in ICF/IIDs, skilled nursing facilities (SNFs), assisted living facilities, and group homes receive training through their employers on how to conduct required investigations. AHCCCS should provide guidance to vendors on the content of such training” Abuse & Neglect Prevention Task Force, 2019, p. 11*) [1.6]
- ✓ Revise APS investigation practices (as documented in the APS Investigation Manual) to include screening for all forms of possible harm, not only the harm directly related to the current incident. Consider language found in the *Arizona Department of Child Safety: Policy and Procedure Manual* as a possible model [1.7]
- ✓ Revise APS investigation practices (as documented in the APS Investigation Manual) to explicitly categorize sexual violence/abuse/assault as a critical incident (Section E, pp. 88) [1.8]

# REPORTING

## SUMMARY OF BEST PRACTICES

Defined as the action or process for disclosing an experience of sexual violence/abuse to others, reporting is well documented within the body of research. This documentation includes recommendations and best practices on the entire reporting process from initial disclosure through trial. Review of the literature (n=26) yielded five key themes within the broader category of reporting. They are:

- **Communication**
- **Fear of Consequences**
- **Lack of Sexual Health Education**
- **Lack of Awareness of the Right to Be Safe**
- **Power Imbalances**

Within the area of **communication**, several authors noted that communication difficulties are often a significant barrier to reporting for individuals with I/DD. One study noted a correlation between verbal intelligence scores and voluntary disclosure of sexual assault. In fact, this correlation found verbal intelligence scores to be a stronger predictor of reporting than age at interview, relationship to the perpetrator, multiple episodes of abuse, type of sex abuse, or more than one perpetrator being involved (Bae et al., 2017). Many others noted that verbal challenges impact sexual violence/assault cases from initial disclosure, through the investigation process and trial. Verbal limitations impede an individual's ability to complete an initial disclosure; to tell the story of their abuse including what happened and who was responsible.

These challenges can also impact the investigatory process (McGilloway et al., 2018) after an initial disclosure is made or sexual abuse/violence is suspected. Antaki et al. (2015) found that individuals with I/DD have more difficulties responding to tendentious questions, which are common in the justice system. These intentionally biased questions are meant to test the integrity and consistency of statements during interrogations and forensic interviews. For individuals with I/DD, these questions are

difficult to recognize and often not refuted, even if the individual with I/DD disagrees with the statement (Bowden et al., 2014).

These challenges continue into the courtroom as individuals with I/DD struggle with typical cross-examination practices. The aggressiveness often employed by attorneys can induce stress, which is known to impact memory. Cross-examination typically relies on complex or confusing questions, utilizes double negatives, and even overtly focuses on discrediting testimony. These practices combined with the lack of accommodations for individuals with I/DD (Antaki et al., 2015) make reporting especially challenging for individuals with I/DD.

Combatting communication related barriers requires the use of specially trained professionals and specially designed processes throughout the investigation and prosecution processes. To improve the trial process, Bowden et al. (2014) recommended replacing traditional cross-examination practices with separate investigative and evidential interviews conducted by a specially trained interviewer. These interviews should take place as soon as possible after an individual has experienced sexual violence/abuse, should be video recorded, and should not be conducted by police officers.

Moreover, individuals with I/DD can provide descriptions of what happened to them. To do this most effectively, they should be asked questions appropriate to their comprehension levels. Active efforts to reduce stress for individuals with I/DD should also be made. Reduced stress can improve accuracy and completeness of testimony for individuals with I/DD (Bowden et al., 2014).

**Fear of consequences and lack of awareness of the right to be safe** further compound the challenges individuals with I/DD face when reporting experiences of sexual violence/abuse. Many of these fears individuals with I/DD experience are the same as those experienced by all victims of sexual violence/abuse, but others are more unique to individuals with I/DD. Specifically, individuals with I/DD can fear losing their independence and/or losing custody of their children. Many individuals with I/DD worry that authorities will be perceive them as incapable of keeping themselves and/or their children safe from harm. They also fear retribution, which given the increased likelihood that an individual with I/DD may depend on the perpetrator for support or care, the opportunity for retribution is great. This is especially true for individuals experiencing a culture of abuse as they may accept the abuse as a normal part of daily life.

Finally, **power imbalances** also play a role in reluctance to report sexual violence/abuse. Forde (1999) found that many individuals with I/DD who were the victims of sexual

violence/abuse depended on their abusers for daily living activities. These daily living interactions not only created greater opportunity for the abuse to occur and be covered up, but also increased fear of retribution. Further, when power imbalances exist within a culture of compliance, the likelihood of disclosure is further reduced (Forde, 1999; Martinello, 2014).

Combatting these issues requires training and access to screening and reporting tools. Training dedicated to empowering individuals with I/DD by providing them with the tools and supports to recognize and report sexual violence/abuse is key. This training must include specific education on individuals' right to be safe and information that works to dismantle beliefs that abuse is the victim's fault or a sign of incompetence (Northway et al., 2014; McGilloway et al., 2018). Body boundaries should also be addressed (Forde, 1999; Martinello, 2014). Specific tools discussed included wallet cards with emergency phone numbers, a self-administered screening tool, and a phone or alert button that is easy to access (Powers & Oschwald, 2004).

## FINDINGS

- \* **Internal policies and procedures are in place.** When asked about internal policies and procedures that include when, how, and to whom to report sexual violence/abuse against individuals with I/DD, the vast majority of day treatment (86%) and group home providers (100%) agreed that these are in place. This survey finding is congruent with the accounts of caregivers who hold dual roles as employees in day treatment programs as well as with the content of documents provided by day treatment programs during the document review. Although this data suggests that the majority of organizations have appropriate rules and procedures in place, there is still a significant gap between current state and best practice.
- \* **Caregivers are not informed of policies and procedures related to reporting.** Less than 10% of caregivers interviewed reported being informed of procedures for reporting sexual violence/abuse. Approximately a third of day treatment providers report that parents are trained on policies and procedures for reporting while approximately 50% of group homes report parental training related to reporting. However, none of the caregivers interviewed had experienced such training nor did they refer to the signage expected by point

#2 of Executive Order 2019-03 or recommendation #2 of the Abuse and Neglect Prevention Task Force (2019, pp. 8). Though documents containing the flowcharts required by recommendation #3 of the Abuse and Neglect Prevention Task Force (2019, pp. 8), none of the interview participants in any subgroup reported being aware of them. These discrepancies are significant and represent a need for additional inquiry.

- \* Consistent with findings in the literature, over 60% of caregivers report that **communication abilities negatively impact reporting**. Caregivers of loved ones with I/DD who have communication difficulties often presented as most concerned that their loved one would experience sexual violence. Lack of access to adaptive technologies and tools (e.g., assistive communication devices) further compound these issues and amplify risk. Those who had already been the victim of sexual violence/abuse faced tremendous challenges during the investigation and prosecution processes including cases being dropped because the individual "couldn't name the person who hurt her." Caregivers who have supported a loved one with I/DD during reporting, investigation, and prosecution as well as FAC representatives reported **insufficient access to research-based accommodations for victims** (e.g. disability specialists, specially trained forensic interviewers with disability expertise).



## RECOMMENDATIONS

Based on understanding of the current state and recommended best practice provided by the literature, the following recommendations have been formulated to support improving systems and conditions for individuals with I/DD in Arizona:

- ✓ Develop questionnaires to be used for routine screening for sexual violence/abuse against individuals with I/DD to reduce the burden of voluntary disclosure [2.1]
- ✓ Reform traditional justice system practices to include accommodations for individuals with I/DD. These could include replacing traditional cross-examination with evidential interviews, actively aiming to reduce stress, and

engaging disability specialists throughout investigation and prosecution processes [2.2]

- ✓ Provide education and training to individuals with I/DD to increase their awareness of the right to be safe, avoid self-blame, and reduce fear of reprisal [2.3]
- ✓ Offer self-administered and proactive screening tools as well as emergency signaling tools to individuals with I/DD to reduce the burden of self-disclosure and be able to call for help [2.4]
- ✓ Provide sex education and training to individuals with I/DD focused on empowerment, boundaries, and reducing vulnerabilities [2.5]
- ✓ Clearly and consistently outline appropriate contingencies when compliance by a person with I/DD is necessary. [2.6]
- ✓ Ensure compliance with the Executive Order 2019-03, point #3 that all state contracts for residential, group homes, and day programs for individuals with disabilities include a requirement for the prominent posting of signage which includes department approved language on how to report abuse and neglect [2.7]
- ✓ Examine practices for approving and denying access to assistive communication devices for individuals with I/DD. Ensure factors for decision-making are equitably applied to all cases. When an individual utilizes an assistive communication device, ensure that icons are loaded that will support disclosure of possible sexual violence/abuse. Establish protocols to ensure that devices are functional and that icons have not been unnecessarily restricted [2.8]
- ✓ Conduct further investigation into the connection between APS and law enforcement/mandatory reporters within service agencies [2.9]
- ✓ Reevaluate how the DD/ALTCS Incident Flowchart and the ACHHHS Incident Flowchart are being communicated. Ensure that these documents are easily accessible, written in plain language, and include all the necessary information to report sexual violence/abuse. Ensure that individuals with I/DD, caregivers and service providers are trained on how and when to use these tools [2.10]

- ✓ Audit “verified” APS cases to discern the extent to which communication difficulties were a factor in the case not being substantiated. Especially for cases that remained unsubstantiated as a result of an “unknown perpetrator (APS Investigations Policy and Procedure Manual, 2019, pp. 44),” ensure appropriate accommodations were provided to individuals with I/DD and that disability specialists were used throughout the investigation process [2.11]
- ✓ Ensure that APS case closure requirements (APS Investigations Policy and Procedure Manual, 2019, pp. 93-95) are being fulfilled. Interview data suggests that required visits and calls are not taking place [2.12]
- ✓ Review and revise APS investigation procedures to ensure that victims with I/DD are safeguarded and provided accommodations throughout the investigation process. Particular attention should be paid to initial response practices that address (APS Investigations Policy and Procedure Manual, pp. 26) guardian notification and initial in-person contact with the client (APS Investigations Policy and Procedure Manual, 2019, pp. 35) [2.13]

# TRACKING

## SUMMARY OF BEST PRACTICES

Defined as the action or process of recording data on allegations of sexual violence/abuse perpetrated against individuals with I/DD and the associated outcomes, tracking is a scant area within the body of academic literature. No peer-reviewed articles met the inclusion criteria applied to this project. As a result, search criteria were expanded to include governmental reports and two reports addressing data collection and record keeping more broadly. Using this set of information, a set of best practice recommendations was established. They include:

- **Clearly define and consistently apply terminology that describes sexual violence/abuse**
- **Clearly define and consistently apply terminology that describes the various types of disabilities**

- Establish data management policies and procedures that include intra- and interagency information sharing
- Establish guidelines for adequate records management, preferably using an electronic document and records management system (EDRMS)

As detailed in the *State of the Research* report, the National Center for Injury Prevention and Control of the Centers for Disease Control and Prevention offered specific guidance in their 2014 report titled, “Sexual Violence Surveillance: Uniform Definitions and Recommended Data Elements, Version 2.0”. The report addressed (a) uniform definitions for sexual violence; (b) data elements for record-based and survey surveillance of sexual violence; and (c) recommended data elements for sexual violence (i.e., identifying information, victim demographics, victim’s first known incident of sexual violence, victim’s most recent incident of sexual violence).

## FINDINGS

- \* **Existing data systems need to be augmented.** Law enforcement officers specifically spoke to a need to update existing police data systems and forms to include check boxes to indicate a case is related to sexual violence/abuse. Doing so would allow for data to be pulled and reviewed, which would assist in training and flagging cases for more specialized supports. Further, group home (95%) and day treatment (81%) providers overwhelmingly reported there are internal processes for recording data on incidents of sexual violence/abuse. However, interviews revealed these systems are often outdated and vary greatly from one organization to another.
- \* **Establish a searchable database.** During interviews, many caregivers reported long, arduous processes of vetting providers to support their loved ones with I/DD. Within that group, 26% expressed concern that there is not an easily searchable database to obtain information about potential providers. Specifically, caregivers seemed interested in understanding the status of background checks and previous or active allegations of abuse. One caregiver expressed concern that in the absence of such a system, parents and providers alike “depend on the memory of someone who has worked here for 30 years” to know whether or not there are concerns about an individual. This leads to

caregiver concern that perpetrators could be moving from one family to another or one agency to another preying on individuals with I/DD.



## RECOMMENDATIONS

Based on understanding of the current state and recommended best practice provided by the literature, the following recommendations have been formulated to support improving systems and conditions for individuals with I/DD in Arizona:

- ✓ Develop well-defined terminology that is used within and across all agencies involved in the welfare of individuals with I/DD. This terminology should be consistent with legislative terminology which should also be reviewed and possibly revised. Specific attention should be paid to language in A.R.S. § 13-1401(3) which offers exception to the definition of sexual abuse when touching or manipulation occurs during caretaking responsibilities **[3.1]**
- ✓ Terminology should define various types of sexual violence/abuse and disabilities **[3.2]**
- ✓ Guidance on definitions and additional data elements useful for tracking sexual violence/abuse is available by the National Center for Injury Prevention and Control of the Centers for Disease Control and Prevention **[3.3]**
- ✓ All agencies involved in tracking sexual violence/abuse and/or individuals with disabilities must have dedicated data management in place that includes policies, procedures, practices, reporting mechanisms, and staff training **[3.4]**

# MONITORING

## SUMMARY OF BEST PRACTICES

Defined as the action or process of ongoing oversight by an authoritative body, to ensure established policies and procedures are effectively implemented and enforced, monitoring is essential to ensuring the safety of individuals with I/DD. Although monitoring is a key mechanism to help safeguard people from violence, exploitation, and abuse (Laing, 2017), there is little peer reviewed literature that addresses the topic. Within the available information though, authors argue that monitoring is best performed by an independent authority (United Nation Convention on the Rights of Persons with Disabilities; CRPD, 2006). This authority should proactively engage in a variety of monitoring actions that include (a) unannounced visits, (b) meetings with patients/residents/participants, (c) published reports that provide the public access to findings, and (d) regular site visits to maintain accountability for implementation of recommendations.

## FINDINGS

- \* **Monitoring practices are inconsistent.** A survey of group home and day treatment providers in Arizona asked a series of four questions related to monitoring. The first question addressed the extent to which respondents agree/disagree that an external authoritative body ensures policies/procedures to reduce risk for sexual violence/abuse are established. 36% of day treatment and 12% of group home survey respondents said that there is not currently monitoring of this kind in place or they are unsure if there is monitoring of this kind in place. The second question addressed the extent to which respondents agree/disagree that an external authoritative body verifies that established procedures are implemented. Similarly, 39% of day treatment providers and 12% of group home respondents disagreed or did not know. The third item asked if an external authoritative body is responsible to follow up on what has been done and what is coming next following a suspected incident of sexual violence/abuse. Twenty-one percent of day treatment respondents reported

disagreement or uncertainty, while 18% of group home respondents said they did not know or disagreed that this type of monitoring is occurring. Finally, the fourth item addressed if individuals with I/DD and their families know who to contact if they believe an organization is being negligent or not following best practices. Within the sample, 15% of day treatment providers, and 3% of group home providers said they were unsure or disagree, that individuals with I/DD and their families know who to contact.



## RECOMMENDATIONS

Based on understanding of the current state and recommended best practice provided by the literature, the following recommendations have been formulated to support improving systems and conditions for individuals with I/DD in Arizona:

- ✓ Consult the National Center for Injury Prevention and Control of the Centers for Disease Control and Prevention for guidance on definitions and data elements useful for tracking and monitoring sexual violence/abuse [4.1]
- ✓ Enact and communicate proactive monitoring practices. Thirty-three percent of caregivers reported a desire for monitoring practices consistent with best practice recommendations to be implemented in the group homes and day treatment programs their loved ones are a part of. Further, caregivers requested channels for monitoring the quality of in home service provision also be addressed [4.2]
- ✓ Look to existing, voluntary monitoring bodies such as Quality First (<https://qualityfirstaz.com/about/>) as potential exemplars after which monitoring programs can be designed [4.3]
- ✓ Ensure that monitoring expectations specifically include sexual violence/abuse prevention and response [4.4]

# TRAINING

## SUMMARY OF BEST PRACTICES

Defined as the act or process of providing individuals with I/DD or those who interact with them the knowledge and skills to prevent, detect, and report sexual violence/abuse against individuals with I/DD, training is a key lever to preventing sexual violence/abuse against individuals with I/DD. The peer-reviewed literature contained a total of 75 relevant articles published between 1992 and 2019. Within these articles, key themes pertained almost exclusively to prevention trainings. These research-based trainings focused on two areas:

- **Sexual health education**
- **Sexual violence/abuse prevention for individuals with I/DD and their service providers**

For most individuals with I/DD expression of sexuality remains a contentious issue (Aunos & Feldman, 2002; Kempton & Kahn, 1999; Löfgren-Mårtenson, 2004; Wings-Yanez, 2014). Despite evidence that their educational needs are similar to or greater than those of individuals without disabilities, sexuality is a topic often neglected for individuals with I/DD (Holland-Hall & Quint, 2017). Individuals with I/DD want friendships, meaningful relationships, and intimacy (Brown & McCann, 2018), yet there is a tension between self-determination and safety when individuals with I/DD lack education related to sexuality and healthy relationships. Formal, individualized, and specific sex education for individuals with I/DD is lacking (McDaniels & Flemming, 2016) and more research is needed to adapt and validate curricula covering key topics such as social skills, body parts, physical and psychological changes during adolescence, reproduction, prevention of sexual abuse, sexually transmitted diseases, and sexual orientation.

As additional programs and curricula are created and/or adopted for use with individuals with I/DD, they should adhere to general effectiveness criteria. These include (a) single-sex groups; (b) high degree of training and experience for presenters; and (c) decision making course components. Additionally, curriculum that address (a) relationships and boundaries; (b) anatomy; (c) sexual intercourse; (d) sexual transmitted

infection; (e) abuse red flags; and (f) positive choice are effective at increasing sexual health education knowledge for individuals with I/DD.

Please note that key points related to best practices in training for other research areas (i.e., detection, reporting, monitoring, tracking, prevention) have been addressed in those sections of this report.

## FINDINGS

- \* **There are significant training needs across the system.** The need for training for providers, individuals with I/DD, law enforcement, caregivers, and others involved in the justice system (e.g., prosecutors, family advocacy centers), was consistently demonstrated across lived experience interviews, provider survey data, and the document review. Best practice suggests directing training resources to provide specific training for each of these subgroups on a variety of issues (e.g., forensic interviews, healthy relationships, sexual education, use of screeners) at consistent intervals.

When interviewing caregivers, law enforcement and FAC representatives, the only trainings consistently mentioned were Article 9 and mandatory reporter training. Neither of these trainings are prevention focused and neither are specific to individuals with I/DD. Further, mandatory reporter training varies significantly by trainer and many interviewees who hold dual roles as caregivers and employees in provider agencies report that this training is also not provided on an annual basis as expected by Executive Order 2019-03.

In addition to augmenting and ensuring consistency for mandatory reporter and Article 9 trainings, there are significant training needs related to prevention, detection, and reporting. Executive Order 2019-03 suggests that AHCCCS, ADHS, and DES, “in conjunction with disability advocates jointly develop training on preventing abuse and neglect, recognizing the signs and symptoms of abuse and neglect, and reporting abuse and neglect for both providers for people with disabilities and for parents and guardians.” Executive Order 2019-03 also states, “AHCCCS, ADHS, and DES shall ensure that all state contracts related to the care of individuals with disabilities include a requirement that all staff, contractors and vendors who have direct interaction with members with disabilities shall annually undergo training in prevention, recognizing and reporting abuse and neglect.” Interview and open response

survey data suggests that providers and caregivers alike would benefit from DDD direction in terms of the content of such training. One provider explained, “we are trying our best to keep up with care of our members. It would really help us to do the right work if DDD gave us some direction [on training].” Similarly, caregivers reported that they expected information related to prevention, detection, and reporting to be coming directly from DDD. Training for caregivers in these areas is critical to ensuring that the majority of individuals with I/DD benefit from best practice as many individuals with I/DD reside and receive services at home.

**\* Training needs to address caregivers, staff, and individuals with I/DD.** When analyzing provider survey data, items that asked about the extent to which day treatment and group home providers had trained stakeholders revealed significant differences depending on the stakeholder group in question. Survey data from day treatment programs demonstrated that 89% strongly agree or agree that their staff have been trained on how and when to report, yet only 27% agree or strongly agree that parents/caregivers have been trained and 52% agree or strongly agree that participants with I/DD have been trained on how and when to report sexual violence/abuse. Survey data from group home providers revealed a similar trend with 97% agreeing or strongly agreeing that staff have been trained, but only 33% of parents/caregivers and 64% of residents with I/DD have been trained.

This trend holds true when training is related to prevention. In the provider survey, day treatment and group home providers were asked if their organization’s prevention methods include trainings and policies informed by best practices and empirical data. The majority (79%) of day treatment providers and (94%) group home providers agreed or strongly agreed that this approach was in place. When providers were asked if they train staff on strategies to prevent sexual violence/abuse, both day treatment (73%) and group home providers (81%) strongly agree or agree that they do. When the audience for such training is parents however, these numbers dramatically decrease to only 41% of day treatment providers and 51% of group home providers strongly agreeing/agreeing that parents are trained on strategies to prevent sexual violence/abuse. These survey findings are consistent with qualitative data obtained in interviews where 0% of caregivers reported having

ever been specifically trained on strategies or tools for preventing sexual violence/abuse.

- \* **Information is flowing through unexpected channels.** Twenty-eight percent of caregivers reported obtaining a significant amount of information related to detection and prevention of sexual violence/abuse against individuals with I/DD from pediatricians, therapists, and non-profit agencies in the community. Parent caregivers also consistently reported learning “the most” from other parents.
- \* **Foundations for quality.** For purposes of training, the research literature recommended regular trainings (i.e., annually) with training adaptations being made according to the developmental stages of individuals with I/DD (i.e., childhood, adolescence, adulthood).



## RECOMMENDATIONS

Based on understanding of the current state and recommended best practice provided by the literature, the following recommendations have been formulated to support improving systems and conditions for individuals with I/DD in Arizona:

- ✓ For individuals with mild to moderate I/DD, parents and providers should consider adopting a research-based sexual health education curriculum to increase the knowledge of young adults with I/DD on topics such as basic anatomy, social skills for healthy relationships, relationship boundaries, information about intimate relationships, personal safety, and red flags for sexual violence/abuse. Caregivers should receive a parallel training to help reinforce these concepts **[4.1]**
- ✓ All individuals with I/DD should receive sexual violence/abuse prevention trainings during key developmental stages such as childhood, adolescence, and adulthood. Consider existing curriculum that has been empirically evaluated and deemed effective for children, young adults, and adults with I/DD. These trainings should cover basic anatomy; explain and practice

discrimination of appropriate and inappropriate situations; teach refusal and reporting strategies; and practice responses to common lures [4.2]

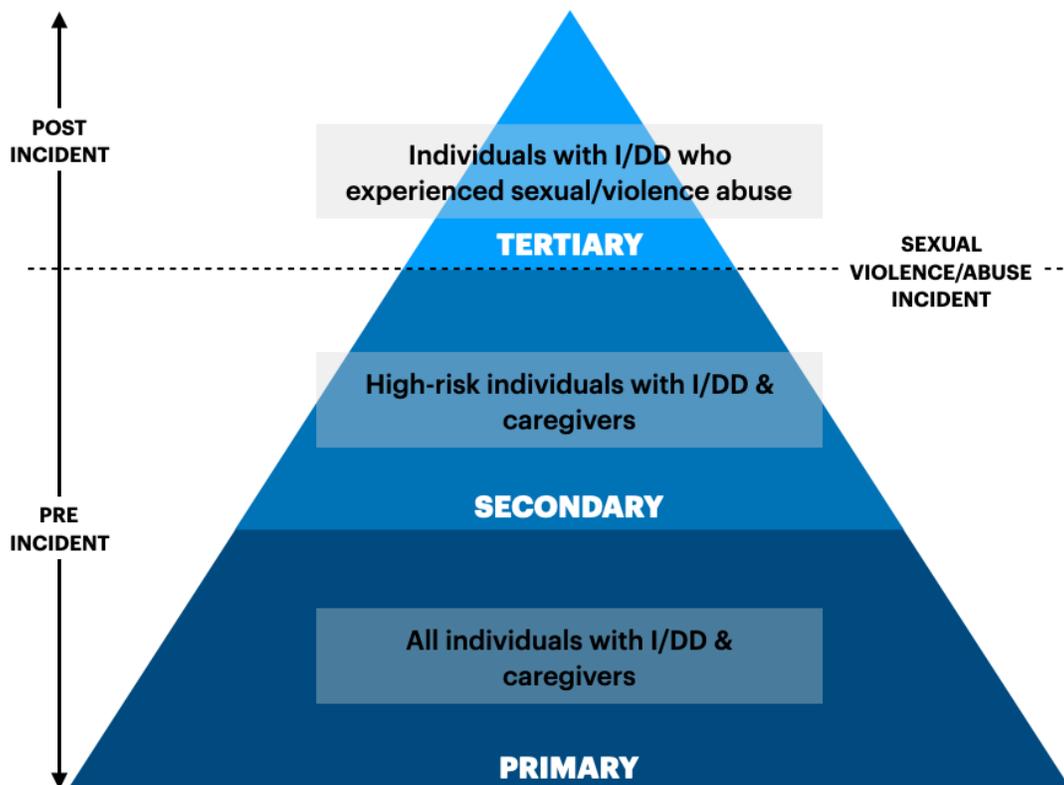
- ✓ Service providers, especially those that work in facilities with individuals with I/DD who are dependent on others for personal care and are unable to seek help or report abuse, should receive regular training exclusively focused on sexual violence/abuse against individuals with disabilities including I/DD [4.3]
- ✓ All trainings designed to address sexual violence/abuse should adhere to best practice standards for adult learning when the audience is neurotypical adult caregivers or staff. These include (a) content focus (i.e., materials specific to individuals with I/DD); (b) active learning (i.e., interactive feedback and discussion, expert/video models); (c) coherence (i.e., training addresses attitudes and beliefs of participants); (d) duration (i.e., sufficient length); and collective participation (i.e., interaction among staff from the same program or group home) [4.4]
- ✓ State agencies and providers should consider collaborating with organizations already doing training that is well regarded by caregivers. Specific mentions during interviews included Raising Special Kids, Ability 360, UCLA and the Autism Society of Greater Phoenix. One caregiver reported that these organizations are “filling the gap of information” for families and caregivers. Although this work did not evaluate the specific trainings offered by these organizations, descriptions provided by interviewees included accounts aligned to best practice recommendations [4.5]
- ✓ Collaborate directly with caregivers when creating additional trainings. During interviews, caregivers offered specific suggestions for training and information/materials that would benefit them. These included information and training on how to best support their loved ones in the transition from childhood to adolescence and then into adulthood, training related to prevention that accounts for individuals’ needs for autonomy, privacy, independent relationships, training, and materials geared toward adolescent and adult individuals with I/DD [4.6]

# PREVENTION

## SUMMARY OF BEST PRACTICES

Defined as the act or process of stopping sexual violence/abuse against individuals with I/DD before it occurs, prevention is of utmost concern to safeguard individuals with I/DD. Literature related to prevention was extensive and thus an organizing framework was developed and applied to better understand the contributions of each relevant piece of literature. This framework classified prevention efforts into three tiers wherein each tier is defined by the target audience, point in time an intervention is applied and the intensity of the interventions applied. Figure 1 visually represents the three-tiered organizing framework.

**Figure 1.** *Three-tiered Prevention Framework*



The intent of each tier within this organizing framework is as follows:

**Tier 1 or Primary Prevention Strategies (PPS)** are designed to prevent sexual violence/abuse against individuals with I/DD from ever being committed. These strategies target the whole population of individuals with I/DD and their caregivers. They are deployed prior to any incidence of sexual violence/abuse occurring. These strategies come in many forms including policies and governance structures, and whole population training and education programs for individuals with I/DD, staff and caregivers.

Primary Prevention Strategies include education/training, policy, governance and oversight strategies, and abuse awareness education. Standards for quality vary depending upon the specific strategy or curriculum used. Sexual health and relationship education as described in the training section of this report are considered PPS as are proactive monitoring practices as described in this report. In addition to training/education and monitoring, abuse education programs like ESCAPE and ESCAPE-DD (Hickston et al., 2015) are primary prevention strategies found to be effective in increasing overall effective decision-making and situation decision-making for individuals with I/DD. These strategies incorporate cognitive and/or behavior-based education that focuses on teaching individuals with disabilities to recognize signs of abuse, to say “no” to an abuser, to leave situations where possible and to report their experiences to the proper people in positions of authority (Wilczynski et al., 2015). Other programs also include self-empowerment and healthy boundary curricula. Some programs are offered online to increase accessibility (e.g. Women’s Safer and Stronger Program). The most effective programs include “booster” sessions to promote knowledge maintenance (Doughty & Kane, 2010).

**Tier 2 or Secondary Prevention Strategies (SPS)** are designed to prevent sexual violence/abuse against individuals with I/DD from being committed but are only deployed to individuals and subgroups (i.e., individuals with multiple disabilities, individuals whose disability includes communication challenges, children) who are at increased risk for victimization and their caregivers. The majority of SPS in the literature are geared toward children. Many of these programs put special emphasis on children learning the anatomical names for body parts and learning appropriate boundaries. Kuckuk et al. (2017) described a program using books to teach children with I/DD at their developmental and intellectual levels using story books. Evaluation of this program was particularly promising as an SPS.

**Tier 3 or Tertiary Prevention Strategies (TPS)** are designed to (a) prevent re-victimization of individuals with I/DD who have already been the victims of sexual

violence/abuse and (b) mitigate the short- and long-term effects of the incident. TPS address the whole population of individuals with I/DD who have experienced sexual violence and their caregivers.

Understanding effective TPS is an area of need within the body of research. Little has been done to identify effective programs specifically designed for individuals with I/DD who have already experienced sexual violence/abuse. However, support and preparation for court, peer support groups (Mikton et al., 2014) and trauma-focused cognitive behavioral therapies demonstrated particular promise. Any TPS should be evaluated for empirical efficacy and no evidence of risk or harm to those receiving the intervention (Saunders et al., 2003).

## FINDINGS

- \* **Prevention beyond the early years.** Consistent with the disproportionality of literature related to prevention of sexual violence/abuse against children with I/DD compared to adolescents and adults, caregivers lamented the challenges of prevention beyond the early years. There are far fewer resources and guidance on how to address prevention for individuals with I/DD after childhood.
- \* **Providers may be doing more than they give themselves credit for.** During interviews, the mean score for caregiver responses to the question, “How much information have state agencies or other service providers provided to you on the topic of sexual violence/abuse against individuals with I/DD” was 1 or, “none,” according to the rating scale descriptions. In spite of this, caregivers went on to cite specific examples of practices providers are utilizing to minimize risk and support prevention of sexual violence/abuse against individuals with I/DD. Specific mentions included the use of two-person protocols for various personal care tasks, and the use of one-way mirrors during therapies. These contributions, especially when taken in context with provider survey data that reports 71% of day treatment providers and 90% of group home providers actively engage in work to prevent sexual violence/abuse against individuals with I/DD in their care paint a contrasting picture. This could mean providers are doing more than they communicate they are when it comes to prevention. This includes having trainings and policies

informed by best practices and empirical data (79% of day treatment and 94% of group home providers) and staff training on strategies to prevent sexual violence/abuse against individuals with I/DD (73% of day treatment and 81% of group home providers)

- \* **Prevention is an act of daily education.** Consistent with best practice found in the literature, caregivers report that prevention is an act of daily education. This includes modeling and reinforcing behavior that supports safety (e.g., leaving the shower with a towel on), redirecting undesirable behavior (e.g., hugging strangers), teaching anatomical names for body parts, establishing expectations for open communication and rules against “keeping secrets,” and routinely discussing boundaries and healthy relationships/interactions. These efforts become more difficult as individuals with I/DD grow older and caregivers unanimously report that having more tools and resources to do this work would be tremendously beneficial.
- \* **Prevention takes quality staff and a culture of responsibility.** Caregivers (100%) and providers (88% of day treatment and 97% of group home providers) alike reported feeling responsible for keeping individuals with I/DD safe from sexual violence/abuse. Similarly, both described extensive efforts to find and hire quality staff to support this effort, however, there seem to be significant barriers to sufficient staffing. Details related to staffing barriers warrant additional inquiry and should address rates of pay, strategies for recruitment, background checks and vetting processes, and strategies for retention.



## RECOMMENDATIONS

Based on understanding of the current state and recommended best practice provided by the literature, the following recommendations have been formulated to support improving systems and conditions for individuals with I/DD in Arizona:

- ✓ Provide high quality, age and developmentally appropriate sexuality education for all people that have I/DD and/or for their caregivers and

professional support providers. These programs should employ the use of multiple teaching methods such as modeling, rehearsal, and practicing skills taught in class. Content of sexual education classes should include topics related to body parts, physical and psychological changes, sexuality as a social skill, reproduction, prevention of sexual abuse, STD education, personal safety skills, and sexual orientation as appropriate for the audience's intellectual and developmental levels [5.1]

- ✓ Effective and independent oversight should be established to monitor services provided to individuals with I/DD. To be considered effective and independent, oversight should have administrative and financial autonomy, oversight personnel should conduct unannounced inspections of group homes, oversight personnel should meet privately with patients to hear potential complaints, and oversight bodies should report findings and follow up on recommendations [5.2]
- ✓ Empirically supported abuse education and awareness programs should be provided and should contain the following elements: (a) teach abuse knowledge early in the training; (b) train individuals on the skills of being able to identify a dangerous situation; (c) train the individual on how to leave the situation without complying with abuse; (d) how to report the situation to a trusted person in a position of authority; (e) if possible, the strengths of both cognitive trainings and behavior based training should be combined so programs include discussion of emotions, thoughts, and feelings as well as the practicing and assessment of skills in situational role-play; and (f) provide "booster sessions" to individuals following initial program to increase knowledge retention [5.3]
- ✓ Trauma-Focused Cognitive Behavioral Therapy should be provided to individuals following experience with sexual abuse [5.4]
- ✓ Conduct additional research into ABA and similar therapies that require compliance from individuals with I/DD, to better understand if there is a relationship between participating in compliance-based therapies and risk for sexual violence/abuse [5.5]
- ✓ Increase communication around prevention practices, specifically naming when practices are intended to reduce risk and/or support preventing sexual violence/abuse [5.6]

- ✓ Pursue further inquiry into staffing needs and challenges as they pertain to preventing sexual violence/abuse against individuals with I/DD. Specifically consider pay rates, recruitment and retention strategies, and background check and vetting processes [5.7]
- ✓ Ensure utilization of the Adult Protective Services Registry prior to hiring by organizations; explore the expansion of this platform for caregiver utilization when hiring/selecting providers. [5.8]

## CONCLUSION

Sexual violence/abuse against individuals with I/DD is a pervasive issue that does not occur within an isolated bubble — its consequences wreak havoc on not only individuals and their families, but on whole communities. Thus, everyone must do their part to reduce the rate at which individuals with I/DD are sexually abused and assaulted. Though more work can be done, especially in the areas of tracking and monitoring, much is already known about best practices that contribute to the safety of some of Arizona’s most vulnerable residents.

Developing a preventative culture in which members are encouraged, supported and educated to ensure the safety of individuals with I/DD is key. This effort must also include a preventative system that is tiered to provide supports that are both broad-reaching and specific to those most vulnerable. These tiers must be designed to engage all community members — including individuals with I/DD, caretakers, providers, families, and state agencies to deepen not only their understanding of the risk individuals with I/DD face when it comes to sexual violence but also how to prevent these acts from occurring in the first place. Individuals with I/DD must know they have right to be safe and their community members should work to ensure that right is respected.

It’s also paramount that this effort provides developmentally appropriate, research-based training to individuals with I/DD so that the information is accessible. This, coupled with training for their loved ones/caretakers, providers, and agencies, is critical to ensuring individuals with I/DD know their rights and are safe from harm. Trainings for everyone should be grounded in research-based best practices and offered on an ongoing basis. Further, training should cover topics directly meant to support prevention (i.e., sexual health education) and those more closely related to detection (i.e., the use of screeners) and reporting (i.e., training individuals and families on when and how to report sexual violence/abuse). And as research identifies more best practices related to

monitoring and tracking, training should also include these areas, especially for state agencies, providers, and law enforcement.

Beyond prevention, community members must also work together to support those individuals with I/DD who have already been sexually assaulted as they pursue justice through both the legal system and personal healing. This includes implementing strategies such as the use of screeners to proactively detect when a person has been the victim of sexual violence/abuse and modifying investigatory and judicial practices (i.e., ensuring a disability specialist is engaged throughout the process, actively minimizing stress) to meet the needs of individuals with I/DD.

Within the state of Arizona specifically, there are existing practices to build upon as community members work together to promote the safety of individuals with I/DD. Recommendations made by the Abuse and Neglect Prevention Task Force should be implemented, continuously monitored, and improved as more becomes known in empirical literature. The work of the Response to Sexual Violence and I/DD Collaborative should be supported and expanded. Prevention and training efforts of providers should be bolstered with developmentally appropriate and disability specific resources and trainings. These efforts will contribute greatly to personal safety for individuals with I/DD, as well as overall community wellbeing in Arizona.