





SEXUAL ABUSE OF ARIZONANS WITH DEVELOPMENTAL AND OTHER DISABILITIES

2019 Legislative and Regulatory Recommendations for Prevention



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When a woman with severe disabilities gave birth at a nursing facility in Phoenix, Arizona in late 2018, it sparked an international outrage. The crisis at Hacienda HealthCare continues to shine a spotlight on issues within Arizona's current system of monitoring, detecting, and reporting sexual abuse of people with disabilities. It has also educated the public how the rape at Hacienda isn't isolated to only care facilities. The Bureau of Justice Statistics National Crime Victimization Survey reports that between 2009 to 2015 people with disabilities were more than three times as likely as those without disabilities to be victims of violent crime, including sexual assault. Of those crimes, 40% were committed by someone they knew well. Those with cognitive disabilities are seven times more likely to be sexually assaulted than the general public; that statistic increases to 12 times more likely if the person with the cognitive disability is also female. These rates may be significantly higher than reported, since they don't include people who live in institutional settings.

While these estimates clearly show the high incidence of sexual abuse suffered by those with disabilities, there has been almost no implementation of policies designed to recognize and stop it until now. The following set of legislative and regulatory recommendations have been developed from a series of roundtables, two public meetings, survey input, interviews, and a policy review. We included a variety of local voices: people with disabilities, state agency representatives, elected leaders, family members, and advocates. A committee of council members, academics, community advocates, state agency representatives, and people with disabilities has also vetted the recommendations.

1. STRENGTHEN "DUTY TO REPORT" LAWS



A. Consistent and annual training: Create legislation requiring staff of any agency or organization who are mandatory reporters under ARS §13-3620 or who have a duty to report abuse under ARS §46-454 to receive, at a minimum, annual training on:

- 1. defining the different types of abuse under current state law, including sexual abuse:
- 2. recognizing signs of these various types of abuse in the population the agency or organization serves;
- 3. how to report abuse and what happens after the report, including protection from retaliation for those who report abuse;
- 4. how to prevent abuse; and
- 5. how to care for the victim who has been abused, including how to refer to behavioral health services or trauma-informed care.

B. Stiffer penalties:

- 1. Elevate the penalty for failing to report abuse of vulnerable adults from a class 1 misdemeanor to a class 6 felony, as consistent with non-compliance of mandatory reporting in child abuse cases.
- 2. Administer financial sanctions with escalating penalties to organizations that fail to comply with any requirement of this provision.
- C. Protecting those who report abuse: Insert legislative language that protects the mandatory reporter from retaliation.

Background:

- A. Many staff at state agencies, schools, provider organizations, and others who work with people with disabilities may not be able to recognize signs of abuse for those who have intellectual disabilities or dementia, or individuals who are non-verbal. Many staff may not know what to do if they see abuse. Unfortunately, there are currently no state legislative requirements regarding training for "mandatory reporting" for children or "duty to report" for vulnerable adults. In addition, there are no consistent training requirements across residential and other Medicaid-funded community-based settings, such as day treatment and employment support services:
 - Group homes are not required to deliver training beyond general "abuse and neglect," which
 is ill-defined by the current law. Current requirements in the Arizona Administrative Code
 (A.A.C. R6-6-808) only state that the Department of Economic Security (DES) Division of
 Developmental Disabilities (DDD) providers require training in abuse and neglect. There is
 no mention of frequency, what abuse and neglect means, or what should be included in the
 training.
 - The state Medicaid agency, the Arizona Health Care Cost Containment System (AHCCCS), requires a one-time training on abuse, including sexual abuse, to earn certification for direct care workers who provide home and community-based services (HCBS).
 - Federal law 42 C.F.R. 483.95 requires training for workers in intermediate care facilities for individuals with intellectual disabilities (ICF-IIDs) that includes learning how to define, report on, and prevent abuse. However, this training doesn't include information on how to recognize it.
- **B.** The penalties for not reporting are less for vulnerable adults than for children. Failure to report child abuse can result in a class 6 felony conviction (ARS §13-3620); for vulnerable adults, it's a class 1 misdemeanor (ARS §46-454). Currently, DDD has no ability to levy financial sanctions against organizations for non-compliance. Protections and penalties need to be more clearly defined, stronger, and equitable.
- **C.** Currently, there are limited safeguards to protect mandatory reporters from retaliation from their employers. Anecdotal reports indicate this may have contributed to an environment of silence at Hacienda an environment in which employees feared for their jobs and their livelihoods if they shared what they knew of abuses and neglect at the facility:

- The Arizona Employment Protection Act (AEPA) offers some protection for wrongful discharge claims and offers limited whistleblower protection. Under this law, an employee may not be discharged in retaliation for disclosing that he/she has information (or a reasonable belief) that the employer has violated, is violating, or will violate an Arizona statute (ARS § 23-1501(3)(c)(ii). We could not identify any protection against retaliation if the complaint was made against another party, such as another staff member. There is also no protection from demotions or other penalties an employer could give the employee who reported.
- Under ARS §46-453, people who report through Adult Protective Services (APS) are
 protected against civil and criminal liability. They are not, however, protected from retaliation
 from their employers; if the report is made outside of APS to include the police, there are no
 immunity laws whatsoever.

2. ELIMINATE DEEMED STATUS LICENSES



Require ICF-IIDs such as Hacienda and the Arizona Training Program at Coolidge to be licensed by the Arizona Department of Health Services. Also, eliminate "Deemed Status" Licensing for healthcare institutions that primarily service children and adults with cognitive disabilities or dementia.

Background: ICF-IIDs are certified by the Centers for Medicare and Medicaid Services (CMS) and are exempt from the Arizona Department of Health Services (ADHS) licensing requirements. As a result, they do not have a state license to operate. These facilities are not accountable to state licensing requirements, and the state cannot use its licensing authority to compel compliance with state requirements. CMS can choose to no longer certify the facilities, and AHCCCS and DES can elect to remove their members if the organization is failing to meet CMS requirements. However, the state currently has no ability to use licensing requirements as leverage to achieve compliance with state standards. It is recommended that ARS §36-591(E) be eliminated to require ICF-IIDs to be licensed by ADHS.

In addition, the Arizona State Legislature passed Deemed Status laws (ARS §36-595) which allow healthcare institutions that are accredited by "an appropriate independent body" (such as the Council on Accreditation) to hold a deemed-status license from ADHS. The agency must accept the accreditation in lieu of a routine annual agency inspection (ARS §36-424(B)). As a result, Arizona healthcare institutions that serve people with cognitive disabilities and dementia avoid routine annual inspections that determine compliance with state licensing standards, although ADHS is still required to respond to licensing compliance concerns (ARS §36-424(C)). Healthcare institutions that serve persons with cognitive disabilities and dementia should be excluded from the ARS §36-424(B) exemption language. Such exclusion would ensure healthcare institutions that serve these groups are inspected annually by ADHS as a condition of their license, not just when a complaint is filed with ADHS.

3. RAISE AWARENESS OF SEXUAL ABUSE AMONG PEOPLE WITH DISABILITIES



Require DDD Support Coordinators to annually review the information below with the member and the family in detail, and in a format that can be understood by the member:

- the right to be free from abuse and sexual abuse;
- how to recognize sexual abuse, physical and emotional abuse, neglect, and financial exploitation;
- how to report abuse; and
- what happens after the report is made.

Background: More than 40,000 individuals with developmental disabilities and their families are served by DDD in Arizona. Some members may live in situations where they are abused and afraid. Some people don't know who to tell about their abuse or are afraid they will get in trouble if they do tell. While we know this population experiences a higher rate of abuse, there is no ongoing required training or notification requirements for members and their families about recognizing the different types of abuse as defined under (ARS §§13-3623 and 46-451), including sexual abuse, and how to report it.

Specifically, there should be a required annual review for physical, emotional, and sexual abuse, neglect, and financial exploitation with DDD members and their families about:

- how to define it
- how to identify it
- how to report it
- what happens after they report, e.g., what happens if their caregiver is removed;
- what protections they have from retaliation, e.g., they won't lose benefits in response
- how to prevent it

Also, parents, family members, or caregivers of the member should be trained about their roles as mandatory reporters. Like staff members, they are subject to prosecution for failing to report abuse. This review of their rights should be performed at least annually by the member's Support Coordinator and offered in a format that is easiest to understand for the individual, such as plain language, American Sign Language, or pictures or videos. At this review, the Support Coordinator should also provide additional training resources to the individual and family that they may pursue on their own. All video resources they share should be captioned. The member should also be provided with the abuse reporting information and phone number to take with them.

4. FUND SEXUAL VIOLENCE PREVENTION AND TRAUMA-INFORMED CARE



Allocate funding to expand the number of trauma-informed counselors, advocates, and forensic nurses who can help support victims.

Background: Arizona is one of only a few states that does not provide any funding to assist victims of domestic and sexual violence or prevention efforts. While there are 24-hour hotlines to help people <u>find a shelter</u>, there are no 24-hour brick-and-mortar rape crisis centers available. There is

also a shortage of trauma-informed counselors overall, with an especially acute shortage of those trained in working with individuals with autism, intellectual, or other disabilities. The funding would be used to expand the number of advocates, medical forensic nurses, and trauma-informed therapists who can help the victim, regardless of disability, to cope and heal. In addition, Arizona needs innovative, community-based, fully accessible, comprehensive service centers for sexual violence survivors that are available 24/7. These centers should include both medical care and trauma-informed counseling to help current victims and those who have experienced sexual violence in the past.

5. ESTABLISH PROTECTIONS FOR VICTIMS WITH DISABILITIES WHO TESTIFY



Create legislation that would carve out special rules to support people with disabilities to give testimony in criminal trials.

Background: Although victims with intellectual disabilities and dementia should be believed, they are often seen as unreliable witnesses. Rarely are their cases ever substantiated, or their perpetrators arrested by police; even fewer of these cases are brought to court. Knowing how to interview people with disabilities is critically important, but many struggle with how to engage in those conversations.

Some individuals with autism or other disabilities can't appear in a courtroom because of their disability-related cognitive limitations. In the case of the young woman at Hacienda, a court appearance is physically impossible. If not done properly, the interview and criminal proceedings can also re-victimize the individual and cause tremendous psychological stress, and even more so for vulnerable adults. The Arc, a nationwide advocacy organization for people with intellectual and developmental disabilities, examined state policies and found at least 32 states have created special rules that give victims with disabilities accommodations to navigate the justice system. This allows their voice to be heard. Unfortunately, Arizona is not among these states.

For example, in Washington state, statutes allow for:

- Representation of witnesses: A victim who is incapacitated or otherwise incompetent shall be represented by a parent or present legal guardian, or if none exists, by a representative designated by the prosecuting attorney without court appointment or legal guardianship proceedings. Wash. Rev. Code § 7.69.040.
- Accommodations: "Dependent persons" (includes people with intellectual and developmental disabilities) are afforded particular rights including: having language explained to them, allowing advocate to be present in court, etc. Wash. Rev. Code § 7.69B.020.

In Maine, state statutes allow for:

Hearsay: An out-of-court statement by someone with a developmental disability is admissible if it describes a sexual act, the court finds that it will promote the well-being of the witness, and the defense has the ability to cross-examine the witness. 15 M.R.S.A. 1205.

Some states have passed legislation requiring their law enforcement agencies or courts to undergo interaction with the disability community or bias training (i.e., AK, KY, LA, MN, NJ, NM, OR).

6. STRENGTHEN THE LEGISLATIVE MANDATE FOR ADULT PROTECTIVE SERVICES



Create legislation that requires APS to investigate every suspected case of abuse, neglect, and exploitation involving vulnerable adults. Educate the community on APS reporting and investigation processes. Allocate funding for more staff and staff training.

Background: Unlike the requirements placed on the Department of Child Safety (DCS) to investigate every allegation of criminal conduct (ARS § 8-471(E) (2)), there is no legislative requirement for APS to investigate each call the agency receives related to abuse, exploitation, or neglect of vulnerable adults. The statute states, "An evaluation is made to determine if the adult is in need of protective services..." (ARS § 46-452(3). According to the 2017 APS annual report, "An APS intake specialist assesses the information provided by the reporting source and determines whether the information meets the criteria necessary to accept an APS report." At the time of this report, it is unclear what this criteria is.

In state fiscal year 2017, APS received an all-time high of 26,785 communications concerning vulnerable adults and this number continues to grow – 13,056 (49%) of those were accepted as reports and investigated. When those reports are investigated, organizations with staff who are the alleged perpetrators state that they receive very little communication from APS. Reportedly, a staff member can be pulled out of the organization for up to six months, while receiving no communication from APS. There is a general lack of communication and confusion regarding the investigative process.

Several questions regarding APS need to be further clarified.

What is APS' criteria for determining when maltreatment calls involving vulnerable adults are investigated? What are the training requirements for the intake staff who determine if a report should be made and an investigation completed? The hotline.number to report abuse is operated Monday - Friday between 7:00 a.m. and 7:00 p.m. and Saturday, Sunday and state holidays 10:00 a.m. to 6:00 p.m. Investigators are assigned to cases Monday through Friday during normal operating hours. If reports are made outside of these hours and they are considered emergencies, callers are advised to call 9-1-1. APS has confirmed that intake staff make a determination using agency criteria from a "national best practice decision-making tool" to determine if a case that is reported is ultimately investigated, but it's still unclear what criteria is used.

It is recommended that APS provide training to the community on what calls are accepted as reports and what the process of reporting and investigation entails. There should also be stronger language adopted to ensure that all cases involving maltreatment of vulnerable adults are investigated. To complete more of these investigations and increase collaboration and communication with stakeholders, more resources for staffing are required.

Why are substantiation rates low? APS substantiation rates, in which the abuse has been verified and the perpetrator has been confirmed, have been consistently low over the years. The reported substantiation rate in 2018 was 2.3%. However, 11% of all cases were verified. When a case is verified, it means there was enough evidence to prove a crime occurred, but a perpetrator could not be identified or the perpetrator was a vulnerable adult caregiver. One example of this would be if an adult with dementia neglected their adult child with a disability while taking care of them.

The substantiation process itself may contribute to lower rates. An APS investigator makes a recommendation to substantiate a report, and the information is then submitted to the Arizona Attorney General's Office where a final determination is made based on evidence submitted. If the case is substantiated, alleged perpetrators have a right to appeal. The substantiation process can take several months. Most cases wind up unsubstantiated.

APS states some reasons that contribute to these difficulties. It all boils down to the evidence:

- Difficulty obtaining medical documents in the timeframe of allegations for clients who have not been to the doctor for several years
- Unknown named caretakers for facility and group home cases
- Clients are nonverbal or have significant memory issues, and there is no evidence to go forward
- Family members account for 26% of the alleged perpetrators. The clients are reluctant to talk to APS or give investigators any information because they are protecting their family member or are afraid.

Further investigation over why these rates are low needs to occur.

The Administration for Community Living released voluntary guidelines for state adult protective services systems. The report found that across the U.S., higher levels of education and more training are associated with higher substantiation rates, but it is unclear what the training requirements are for APS staff members. In addition, relationships with police and forensic centers strengthen investigations, but it is unknown how strong these relationships are in Arizona.

Both APS staff and representatives of law enforcement must be properly trained to interact with people with disabilities so that the information they gather and the outcomes of their investigations provide justice to those who have been victimized. It is also advised that APS strengthen connections with the Arizona Center for Disability Law (ACDL) to better coordinate investigation efforts. ACDL has federal access authority to conduct investigations in facilities. Their attorneys can talk to residents privately and are trained in communicating with people with disabilities who may have been victimized.

7. PUBLICLY POST ALL RESIDENTIAL MONITORING REPORTS



Require DDD to post performance/monitoring reports of group homes and adult developmental homes

Background: Individuals and families only receive limited information about residential settings before they are asked to decide where to live. They don't have access to information regarding how these settings are performing. The monitoring reports are not posted online, as they are for ICF-IIDs, assisted living facilities, nursing homes, adult foster care, and other settings licensed by ADHS. To help individuals and families locate the right residential settings for them, DDD should publicly post performance reports.

ADDITIONAL CONSIDERATIONS

The previous recommendations are only the beginning of changes community stakeholders and families want to see. The disability community struggles with several other issues, including:

- 1. Tribal communities: The victim in the Hacienda case is a member of the San Carlos Apache Tribe. Tribal members who live on sovereign nations in Arizona face additional barriers when reporting and prosecuting sexual violence. One reason is due to confusing law enforcement jurisdictions, which can include tribal police, federal agencies, county officials, or others, making it easier for a case to "fall through" the many cracks. There is an urgent need for more research into solutions to prevent sexual abuse of tribal members with disabilities, whether they live in a sovereign community or another area.
- 2. Background checks: Arizona's fingerprint clearance cards ensure that potential employees are not included in the criminal history records of the state of Arizona and the FBI. These cards are valid for six years. Within those six years, the Department of Public Safety emails employers if an employee is added to those criminal records. Separately, the APS registry is updated weekly and lists perpetrators who have been substantiated to have committed abuse, neglect, or exploitation against a vulnerable adult. The perpetrators placed on this list may not have a criminal charge that would be identified through regular background checks. It is recommended that organizations that interact with vulnerable adults or children conduct at least annual APS and DCS central registry checks for all employees. To make it easier for organizations to check these registries and ensure all names are found, it is recommended that APS create its registry in a format that may be uploaded to data management systems instead of the current PDF version.
- 3. Staff shortage crisis: To recognize sexual abuse in some individuals with intellectual disabilities, the staff must get to know them to recognize any physical or behavioral changes. That becomes very difficult when the average turnover rate in the disability service industry is high. A 2018 report by the Human Services Research Institute as part of its National Core Indicators project finds that across the U.S., 46% of direct support professionals turn over in one year. The same report also finds that there is a shortage of staff available, with about 12% of direct service positions remaining open at all times. When the Hacienda rape was discovered, there were 31 part-time and full-time positions open at the facility. Following disclosure of the recent scandal, Hacienda was forced to hire a third party to fill gaps immediately.

Staff shortages affect the safety and quality of care of people with disabilities, and the problem is only getting worse. People with disabilities are living longer, and there continues to be a growing number of seniors in need of care. In this field, staff members receive low pay, require little education, and often face high stress in under-staffed organizations, which has been the case for years. A viable solution to eliminate this issue has yet to be found.

A task force needs to be created around staff shortage and quality, with a focus on driving systems change. There needs to be a frank discussion about how this issue is impacting the most vulnerable citizens in our community and what actions are needed to fix it. Creating a stable workforce would begin to address most of the quality of care and abuse issues faced now and would help people with disabilities live the life they desire.

4. Victim referrals to trauma-informed counselors: People with disabilities, including those who are non-verbal and who have been sexually abused, can positively benefit from trauma-informed counseling. Currently, it is unknown if survivors are receiving it. State regulations mandate that if a DDD member appears to be abused, neglected, or injured, they are to receive an immediate medical examination by nursing staff or a licensed physician (A.A.C. R6-6-1603). But beyond the medical examination, it is not clear what type of counseling services members may receive. This needs to be further investigated.

CONCLUSION

Carrying out each of these recommendations will require resources, whether it be money, time, staffing, or something else. In the wake of the Hacienda case, what Arizona decides to do, or not do, and how the state leverages its resources will signal to Arizonans with disabilities, their families, and the rest of the country where their safety and well-being stand among a list of competing priorities. Fortunately, preliminary steps have been taken. A bipartisan group of legislators and congressional staff have discussed with stakeholders how to prevent another Hacienda incident from happening. The Office of Governor Doug Ducey has also been keenly focused on addressing this matter and will soon convene a work group to determine what data is needed to improve the state's response to sexual violence against people with disabilities.

Moving forward, a group of stakeholders convened by the Arizona Developmental Disabilities Planning Council (ADDPC) will continue to meet. The next goal is to invite law enforcement and prosecutors to create and implement an action plan to ensure that Arizonan's with disabilities are safe from sexual abuse. The ADDPC will also release a grant solicitation for research on the impact of sexual violence on people with developmental disabilities in Arizona. While the ADDPC will not be able to comment on any drafted legislation, it will continue to share information to ensure Arizona improves its response to serving all people – including people with disabilities. To find out how to get involved or for more information, visit addpc.az.gov.



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The Arizona Developmental Disabilities Planning Council is made up of individuals with disabilities, family members, professional stakeholders and state agency representatives appointed by the Governor of Arizona. We envision one community working together to achieve full inclusion and participation of people with developmental disabilities. We collect and publish research, fund grants, advance inclusion through advocacy and promote self-determination.