



Arizona's Crisis Response & People Who Have Intellectual/Developmental Disabilities (ID/DD):

2022 Policy Recommendations



January 2022

Acknowledgements

We wish to thank staff representatives Arizona's Department of Economic Security Division of Developmental Disabilities (DES-DDD) for providing important feedback on this report's contents related to its program.

In addition, we want to acknowledge the following individuals and organizations who provided information and/or reviewed and provided valuable contributions to aid in the completion this report.

Anne Ronan, Arizona Center for Law in the Public Interest
Erica McFadden, Jason Snead, Melissa Van Hook, Scott Lindbloom
& Steve Freeman, AZ Developmental Disabilities Planning Council
Diana Wilson, Aspen Behavioral Counseling
Cynthia Macluskie, Autism Society of Greater Phoenix
Maureen Casey & Denise Resnik, First Place Global Leadership
Institute
Kelly Carbello, MSW, Just Kelly, LLC
Raylah Pillar, ASU MSW Intern

*Staff representatives of AAPPD, AHCCCS, AZ POST, Mercy Care Arizona, and Arizona Complete Health were provided working drafts of this document for feedback before this report was finalized.

ARIZONA'S CRISIS RESPONSE & PEOPLE WHO HAVE INTELLECTUAL/DEVELOPMENTAL DISABILITIES (ID/DD):

2022 POLICY & LEGISLATIVE RECOMMENDATIONS

The following set of legislative and state policy recommendations have been developed from a series of meetings with family members and state officials, as well as a review of policies related to the crisis response system in Arizona. The majority of the recommendations are intended for state agencies, health plans, law enforcement and organizations to strengthen their own policies to better support people with ID/DD in crisis. A few legislative changes are also needed to better support law enforcement and the crisis response system.

In the following situations, individuals who have ID/DD and their families were left to call the police when behavioral health services were out of reach.

Scenario #1: Fearing for her life and not knowing where else to call, a non-English speaking mother called the police. Her adolescent son was having a mental health crisis. He is nonverbal and has autism. This was the ninth time she's called in the span of eight months. Each time the situation has escalated further, resulting in her son attacking the police during this latest incident. Prior to this call, her son has been denied behavioral health services due to his behavior.

Scenario #2: A parent received a court order to place her adult son who is suicidal, has schizophrenia, and autism in a level 1 treatment facility. She called crisis services to get the services he needed and to fulfill the court order. Crisis services called the police to transport her son, but they didn't send anyone from crisis services to help. The police didn't do anything because her son was inside his own home and not committing a crime. The mother was told to go home. She did not know where else to turn and was fearful for her son's safety.

Their loved ones remained in danger even after these calls were made. Police intervention is not the answer to an unresponsive behavioral health system.

Starting October 1, 2019, the Arizona Health Care Cost Containment System (AHCCCS) and Arizona's Division of Developmental Disabilities (DDD) integrated behavioral and physical health systems under DDD's contracted health plans. AHCCCS stated that this care model "will enhance care treatment between providers and improve member health."

What was not integrated in this model, however, were crisis services. These services continue to be offered to all Arizonans, whether they are insured or not. They are operated through separate health plans – Mercy Care, Arizona Complete Health, and Health Choice Arizona – and administered by Tribal and Regional Behavioral Health Authorities (TRBHAs/RBHAs).

Administration of the crisis system is complex as there are several layers of administration, starting with AHCCCS. AHCCCS is responsible for allocating funds through a competitive bidding process to the multiple Regional Behavioral Health and Tribal Behavioral Health Authorities (T/RBHAs) and for overseeing administration of those funds. The selected health plans, Mercy Care, Arizona Complete Health, and Health Choice Arizona were awarded RBHA contracts for central, southern, and northern Arizona respectively. As of October 1, 2022, Care1st, part of Arizona Complete Health, will become the RBHA for northern Arizona. The TRBHAs/contracted health plans then sub-contract with provider networks and individual practitioners to provide services to their members. For DDD members, AHCCCS contracts with DDD separately to provide general mental health services under DDD’s contracted “integrated” health plans, with the administration of crisis services provided separately by the T/RBHA.

These separate systems, i.e., the DDD-contracted health plans, the T/RBHAs’ crisis health plans, AHCCCS, and DDD – have failed in consistently coordinating and providing much-needed services to members in crisis. In effect, albeit unintentionally, this carve-out has perpetuated fragmented systems that ultimately harm the ID/DD community and their families. Following, the key issues are clarified, and recommendations are proposed for members of the ID/DD community to receive the behavioral health services they need to stay safe and healthy. While these recommendations are targeted to DDD members specifically, some recommendations will benefit the larger population in need of behavioral health services – especially among those who have disabilities.

1. REQUIRE STRONGER ACCOUNTABILITY OF CRISIS SERVICE PROVIDERS



- A. AHCCCS should require T/RBHAs to monitor their providers more closely by directly obtaining member feedback to ensure providers are providing services, following up, and communicating with member health plans. There should be full public transparency and reporting of findings.**
- B. AHCCCS should work with the ID/DD and larger disability community to set benchmarks and standards for T/RBHAs and crisis providers to ensure services are timely, accessible, inclusive, and effective.**

Background:

A. Crisis services for mental health include crisis lines that accept all mental health crisis calls and dispatch support based on the assessed need of the caller; mobile crisis teams dispatched to wherever the need is in the community; and crisis receiving and stabilization facilities that serve everyone that comes through their doors from all referral sources. Mobile crisis service providers are expected to follow up with individuals served to determine if the services to which they were referred were provided in a timely manner and met their needs.

According to AHCCCS policy, the crisis services contractor is responsible for *“ensuring crisis follow up and care coordination for individuals who have engaged in the crisis system within 72 hours of receiving a crisis service.”* In addition, *“the member’s health plan shall ensure that post crisis care coordination and service delivery occurs when an enrolled member engages in crisis services, with the objective to address the individual’s ongoing needs, and ensure resolution of the crisis...Care coordination shall occur between the member’s Contractor of enrollment...including T/RBHA or Tribal ALTCS, the AHCCCS-RBHA Contractor and crisis providers serving the member.”*

However, the T/RBHAs and their providers – do not consistently comply with contractual obligations set forth by AHCCCS, specifically the reporting and follow up requirements. As a result, families are reporting an inability to receive behavioral health services after multiple engagements with crisis services. In too many Arizona communities, the “crisis system” is still being unofficially handed over to law enforcement, sometimes with devastating outcomes. The current approach to crisis care is patchwork and delivers minimal treatment for some, while others simply fall through the cracks. For a person deemed to be a danger to themselves, the standard procedure is for crisis services to call police, who then may or may not respond, depending on how the situation is described. According to the [National Guidelines for Behavioral Health Crisis Care](#), *“the current approach to crisis care is patchwork and delivers minimal treatment for some people while others, often those who have not been engaged in care, fall through the cracks; resulting in multiple hospital readmissions, life in the criminal justice system, homelessness, early death and even suicide.”*

AHCCCS reports that health plans are required to create corrective action plans and compliance actions when providers fail to meet required standards. For example, delays or difficulties in accessing care are required to be reported and are triaged for quality of care (QOC) concerns. AHCCCS and the health plans track reported incidents of failed care coordination through the complaint, grievance and QOC processes, which is not publicly reported. However, when a crisis service provider does not follow up, there is no penalty for that provider. Failures in communication continue to occur, indicating the current AHCCCS process of monitoring needs to be re-examined. The T/RBHAs may be reporting to AHCCCS and the DDD-contracted health plans or even to DDD when a crisis incident occurs, but it is generally through email with no consistent follow up, as reported by DDD members and their families.

In addition, Mercy Care reports that they ask the behavioral health providers to evaluate themselves. To that end, the providers institute their own surveys to determine member satisfaction, which is not a credible way to highlight gaps that occur. AHCCCS, the health plans or a neutral external organization should be conducting surveys or gathering input of people touched by crisis to gain feedback on provider performance. Police should also be included in surveys and other feedback efforts to monitor and improve contractor performance and better coordinate communication protocols.

According to the [National Guidelines for Behavioral Health Crisis Care](#), effective crisis service models utilize outwardly facing performance reports measuring a variety of metrics such as call volume, number of referrals, time-to-answer, abandonment rates, and service accessibility performance. Solari Crisis and Human Services (formerly Crisis Response Network) uses [dashboards](#) to monitor performance of providers in Arizona; however, there is no indicator tied to service accessibility performance. The currently reported data needs to be enhanced.

In addition, to better understand where gaps occur, there should be very focused audits of a statistically significant number of crisis calls involving people who have ID/DD and other disabilities selected by an external organization at least annually. The audit should include the following:

- ✓ Did crisis respond and within what time frame
- ✓ Did crisis call the police? If so, why?
- ✓ Who handled the crisis, e.g., the police, the crisis provider, the mental health system?
- ✓ If transportation was not provided by the crisis provider or the health plan for the member in crisis, why not?
- ✓ How was the crisis resolved?
- ✓ Did the crisis provider notify the member health plan?
- ✓ Did the crisis provider follow up to make sure the health plan provided the necessary follow up services?
- ✓ What did the health plan do in response?

B. AHCCCS should work with the ID/DD community and their families and law enforcement to establish standards of care in crisis response. These standards should be included in all contract and monitoring requirements. Any monitoring data received should include – and be disaggregated upon analysis by primary disability, e.g., epilepsy, cerebral palsy, autism, intellectual disability, etc. to better identify patterns in response or gaps. Understanding in more detail the barriers by disability type may lead to better understanding around current gaps pertaining to a specific disability diagnosis and may improve response.

(Note: When this recommendation was brought to AHCCCS' attention, a representative pointed to the role of the DDD Justice Liaison to address this. However, allocating these activities to one position removes the voice of the individuals and families most impacted.)

2. MONITOR COMMUNICATION PROTOCOLS



AHCCCS and DDD need to monitor and follow up to ensure contractual requirements are implemented and members are receiving follow up services.

When a crisis incident occurs involving a DDD member, AHCCCS requires notification from the crisis response provider to the DDD member's plan of enrollment. In turn, the DDD-contracted health plan is contractually required to notify DDD's Behavioral Health Administration to ensure the individual is connected to needed on-going mental health services. Additionally, AHCCCS reports that if a 9-1-1 call is triaged through the crisis system, there would be notification to the T/RBHA. The crisis provider also communicates with the member's health plan.

In 2019, DDD's Behavioral Health Administration began receiving daily reports from the crisis providers, Solari and Arizona Complete Health. They put this information in an electronic database called Focus to notify Support Coordinators of crisis incidents. Support Coordinators are notified daily. Depending on the incident, Support Coordinators have between two and five business days to respond. They may need to follow up with the member to modify their service plan to include behavioral health services and/or home and community-based services and respite that can better support the member and their family. DDD also creates monthly reports formatted by district. If there are more than five crisis incidents a month involving a member, the Behavioral Health Administration will reach out to the Support Coordinator to provide assistance.

Despite these AHCCCS and DDD requirements, some staff of DDD-contracted health plans and DDD report they are not always notified by the T/RBHAs or the crisis service provider of the incident. Crises for these families continue in the absence of necessary ongoing behavioral health services and supports.

There should be follow up meetings with DDD, DDD's contracted health plans and T/RBHAs on an ongoing basis to improve communication. These meetings should happen at least monthly to ensure they are all working together and providing feedback. In the last few weeks, some of the health plans have stated they started notifying DDD and Support Coordinators through email when a member was involved in crisis response services; however, some DDD staff deny they are consistently getting these communications. All communications should be documented and tracked at the administrative level of all agencies and organizations involved to ensure there is follow up occurring.

AHCCCS should also more broadly disseminate their current publicly available phone number for feedback on crisis response. This number should be disseminated to individuals, families, law enforcement, and providers. If people are experiencing any delays or need help in accessing physical or behavioral health services, the phone numbers for

the **Clinical Resolution Unit** are **602-364-4558** or **1-800-867-5808**. There is also a [website](#) where this information can be accessed.

To better track communication breakdowns, AHCCCS should request the number of members with who were engaged with crisis response from crisis providers and DDD-contracted health plans. The T/RBHAs can also be asked for these numbers, as well as DDD. Comparing these numbers would identify patterns in communication so any failures may be rectified, and member services may be better coordinated.

(Note: A crisis collaborative meeting between Mercy Care, crisis providers, and DDD was established by Mercy Care, and the first meeting took place on 12/14/2021. There is a plan to meet quarterly for ongoing collaboration to support members in crisis.)

3. TRAINING, RESOURCES, AND POTENTIAL LEGISLATIVE CHANGES ARE NEEDED FOR THE JUSTICE SYSTEM AND LAW ENFORCEMENT



- A. AHCCCS should require MCOs' Justice Liaisons, including those at DDD, to have a standard email box and phone number that is easy to access by health plans, the justice system, law enforcement, and the general public when the interaction involves law enforcement, jail or the judicial system.**
- B. All police departments should be legislatively required to track and annually report to AZ POST the percentage of Crisis Intervention Team (CIT) trained officers they have on staff. Police, especially in rural areas, would benefit from training to better support interactions with the ID/DD community.**
- C. Current state legislation regarding police apprehension and transport of people requiring court-ordered emergency evaluations and potential transport of those in crises needs to be re-examined. Additional funding also needs to be allocated to increase the number of mobile crisis teams throughout the state.**
- D. Jails/prisons should be monitored to ensure they are consistently collecting disability data and accommodations needed at intake.**

Background:

A. Police spend much of their day interacting with people with behavioral health issues, and on some occasions, people with ID/DD. Law enforcement finds themselves called to incidents involving the same individuals repeatedly, and they remain disconnected from resources. Those police officers who attempt to intervene find themselves searching for numbers to get help for these individuals. DDD-contracted health plans share that there is a lack of consistent understanding among police precincts on how and when to connect

with member health plans. This lack of understanding is disproportionately represented in rural areas of the state. The DDD-contracted health plans expressed that they are unable to connect with every precinct to educate law enforcement. Instead, they need a general number that police officers can call for assistance.

AHCCCS maintains that police should only be contacting the T/RBHA crisis lines, as police are not able to identify a person's health plan or eligibility. T/RBHAs are required through their AHCCCS contracts to support, train and interact with local law enforcement. Crisis call centers are the most effective contacts for police and are responsible for Mobile Team dispatch, care coordination and notification to health plans if a person is an AHCCCS member. However, sometimes these calls fail, and police get repeated crisis calls involving the same individual with the individual having never received any assistance or follow up from the T/RBHAs.

AHCCCS contracts require Justice Liaisons that are housed at each DDD-contracted health plan and at DDD. According to AHCCCS, the Justice System Liaison is the single point of contact for justice system stakeholders, including, jails/prisons/detention facilities, courts, law enforcement, and community supervision agencies. This position is responsible for ensuring care coordination of justice-involved members and for oversight and reporting of Justice System Reach-in Care Coordination activities. It serves as the single point of contact for justice system stakeholders engaged in arrest diversion or incarceration alternative initiatives, as well as crisis system utilization and specialty court programs. According to AHCCCS, health plans and their Justice Liaisons should be notified by the crisis system of interactions with enrolled members.

In essence, the DDD Justice Liaison position is staffed to ensure that DDD members are connected to needed services throughout the times they are engaged with the judicial system and law enforcement. DDD collaborates with the health plans to discuss shared members who are justice involved and conducts multidisciplinary meetings internally on a monthly basis to plan and support justice involved members.

However, DDD has a differing view than that of AHCCCS of the role of their Justice Liaisons. According to DDD's emailed statement:

“the DDD Justice Liaison is not the DDD contact for crisis or law enforcement but is there for jails/detention/probation etc.... Crisis works with the DDD Behavioral Health Administration, law enforcement is supported by the DDD community engagement, Behavioral health Administration and OIFA Advocates along with Support Coordination and Network. After hours, calls are received at 844-770-9500.”

Many are confused over who to call within DDD with so many positions involved, leaving the DDD Justice Liaison to be under-utilized. As of fall 2021, out of over 40,000 DDD members, there were only 54 that were being monitored by the DDD Justice Liaison.

General contact information for these Justice Liaisons are shared with the detention facilities, jails, probation officers, and the T/RBHAs. They are not, however, shared with law enforcement for coordination, which adds to the confusion for law enforcement over where to go for help. Member health plans and their Justice Liaisons, should be notified by the crisis system (which includes police) of interactions with enrolled members.

It is important that the Justice Liaison contact information that is shared, including phone number and email, is general contact information that is always responded to by someone who is knowledgeable. Many crises occur after normal business hours. To that end, after-hours information should also be provided on Justice Liaisons' voice mail greetings and email responses. All contact information must remain the same no matter who is in the position to ensure continuity of communication.

B. The ID/DD community continues to struggle with law enforcement, especially in rural areas of the state. For example, law enforcement doesn't always understand why a person with autism may not respond to police orders or may be showing behavior that seems non-compliant. Exacerbating the problem, families of ID/DD members have often reported that during interactions with police, their loved ones have been viewed as under the influence of drugs, confusing their ID/DD diagnosis with substance abuse. Crisis Intervention Team (CIT) training helps those officers who choose to participate understand how to de-escalate crisis situations. Rural areas, however, struggle with the ability to participate in CIT training because they lack resources and manpower to cover for those being trained. To highlight where resource and training needs are and improve law enforcement response, police departments should be required to track the percentage of officers that are CIT-trained. There also should be authority given to the Arizona Peace Officer Standards and Training Board (AZPOST) by the state legislature to annually collect and report this data.

Consistent disability training also needs to occur. Be Safe is a training involving law enforcement and individuals with ID/DD that helps both get acquainted with each other and sets expectations from both parties. In Arizona, the Be Safe program started with a partnership between the Autism Society of Greater Phoenix and local police departments. Teaching safe behaviors directly and explicitly to individuals with learning needs is essential for promoting safety for themselves and others. The program also gives police a better understanding of individuals in the disability community, and it gives officers a chance to interact with the community they serve. These trainings have resulted in more positive, safer interactions between these individuals and police.

The Southwest Autism Research and Resource Center (SARRC), in collaboration with VirTra, a global provider of training simulators for law enforcement, developed a comprehensive [training](#) targeted specifically to police officers on interacting with individuals on the spectrum. These virtual training scenarios were developed using individuals with autism. The simulation enables first responders to practice interacting, identifying and de-escalating incidents and receive immediate feedback on their efforts.

C. The culture of policing is focused on compliance and enforcing the law – not in stabilizing a mental health crisis. Police should be better supported when confronting these situations. The following story shared by a local police officer highlights the key issues officer experience:

For four months, a man who lived on the street constantly stole items so he could get arrested and taken to jail. He needed medication and placement in a mental health facility, but was unable to receive either, despite police attempts to help. The County Attorney dropped charges against the man because of Covid-19, so his hope to go to jail to get services was dashed. He committed suicide shortly after. This is a common occurrence.

Crisis response should always be operated by trained crisis response mobile teams led by mental health providers and not automatically be diverted to police. Crisis mobile teams can provide non-emergency medical transportation if a person is willing to engage in services and is safe to transport. These mobile teams, however, do not have the legal authority to execute a pickup order issued by the courts. Arizona police respond because they statutorily have to, resulting in much of officers' time spent on transporting individuals to receive court-ordered mental health evaluations. Under *Arizona Revised Statute* §36-525, "a peace officer, on the advice of the admitting officer of the evaluation agency pursuant to section 36-524, subsection E, shall apprehend and transport a person to an evaluation agency." There is no flexibility for mental health agencies to provide transport in these situations. This can put both the officers and the individual in potentially unsafe situations. Officers aren't always adequately trained in de-escalating mental health crises, especially among individuals who have ID/DD.

On the other hand, the statute also gives officers the discretion regarding apprehending and transporting an individual if there is no emergency order. In response, there is marked confusion among police departments about what they should and should not do in crisis situations. Recently, a mother called crisis response to fulfill a court order to transport her suicidal son who had autism to a facility from his house for an evaluation. Following state statute, crisis response called the police to transport this young man to the hospital for evaluation, but the police refused to enter his home to apprehend and transport him stating they had no authority to enter the home without a warrant and that "suicide isn't a crime." While this response is against state statute, if there hadn't been a court order, the decision on whether or not to intervene in a potential suicide can vary from one officer to another, and for good reason.

The rules requiring police intervention themselves are unclear. The exigent circumstances doctrine permits warrantless entry when there are both exigent circumstances and probable cause. Emergency situations involving endangerment to life fall squarely within the exigent circumstances exception. The probable cause requirement may be met where officers reasonably believe a person is in danger. Even then, the warrantless entry or

search must be strictly limited to addressing the exigent circumstances presented. The threat must also be deemed as imminent, meaning ‘would it occur before officers could obtain a warrant or court order?’

The written [opinion](#) of a recent U.S. Supreme Court case highlighted that it is perfectly constitutional for police to apprehend and enter the home of someone without a warrant in cases where the person is suicidal:

"The Fourth Amendment does not require officers to stand idly outside as the suicide takes place. To be sure, courts, police departments, and police officers alike must take care that officers' actions in those kinds of cases are reasonable under the circumstances," ...

What is considered reasonable? How officers perceive the answers to these questions may lead to varied responses in the same situation. An [article](#) in *Police* posits, "Police are legally more protected if they do nothing than if they intervene."

This variability of police response and at times, lack of action and access to care, creates hostility and frustration among many families. A protocol should be established by all police departments that relegates them to apprehension and transport of people in crises only after mobile crisis teams or behavioral health agencies cannot intervene. Otherwise, there will continually be inconsistent police actions that can facilitate negative outcomes and leave families confused.

Without behavioral health providers taking a driver's seat, more of the ID/DD community will inevitably wind up in jail, hurt, or shot and killed. Additionally, there needs to be an increase in funding to support more trained non-emergency mobile teams throughout the state that can respond to the growing number of people in crises and take pressure off of law enforcement. Recognizing this as a serious issue, the U.S. Department of Justice [awarded \\$34 million](#) in December 2021, to support community crisis response.

D. After a person is booked into jail, unlike people who have a Serious Mental Illness (SMI) diagnosis, jails do not always receive information that identifies the member as with DDD or as having a disability and in need of accommodations. Thus, jails are not ideal for coordinating needed services for DDD members. Without accommodations in the justice system or an advocate, these members may accept responsibility for something they didn't do or not receive the accommodations or care they need while in jail. It is important that intake documents at city, county, and state jails/prisons consistently collect disability and health plan data, and the booking information is transmitted to the health plans and Justice Liaisons across the state to ensure these individuals are not unfairly discriminated against and they receive needed services in response to their crisis.

4. DDD SUPPORT COORDINATORS AND HEALTH PLANS REQUIRE ADDITIONAL TRAINING ON BEHAVIORAL HEALTH NEEDS OF THE ID/DD COMMUNITY



To increase behavioral health services referrals from DDD Support Coordinators and the health plans, training is needed on behavioral health services and their associated benefits for ID/DD members (including nonverbal members).

Background: [Research](#) has found that 30-50% of children and youth with ID/DD have a psychiatric diagnosis, which can have serious effects on the person's daily functioning. It can interfere with educational and vocational activities, jeopardize housing options, and disrupt family and peer relationships. Therefore, it is imperative that accurate diagnosis and appropriate supports and treatment be obtained in a timely manner.

However, families are reporting that some Support Coordinators are advising them that if members are nonverbal, they cannot benefit from behavioral health services. DDD leadership has reported they have not heard these complaints, but they “do hear occasionally of behavioral health agencies indicating therapy will not benefit a nonverbal or I/DD member; we collaborate with the Behavioral Health Administration to provide education to the agency if this occurs.” This misperception results in families not receiving necessary behavioral health services over extended periods of time. A mother recounts her attempts to get help from her Support Coordinator for her 17-year-old son, due to his violence. The Support Coordinator's solution was to create a safety plan for the family to hide from the child. With the continued failures in coordinating behavioral health care by Support Coordinators, the question becomes would DDD-contracted health plans be better suited for this task?

DDD does not have a case management system to adequately support members with behavioral health issues in their member service plans. They are also not adequately trained on services and supports needed for DDD members with behavioral health issues. In 2017- 2018, in anticipation of the integration of behavioral health to the acute health contracts for DDD, DDD Support Coordinators and targeted DDD staff were required to complete training on ID/DD and mental health issues within a set timeframe. DDD is currently revising and updating additional training in this area. DDD suggests they are well-resourced to help members navigate behavioral health resources with the following comment:

Technical assistance on navigating behavioral health services is available from BH complex care specialists and assistance with advocating is available from BH Advocates. Refer to procedures BH-003, BH-011, BH-10 for clarity on internal processes. In addition, the support coordinators may escalate member issues internally for additional assistance and BH Liaisons or care managers from the health plans are available to assist.

However, the comment highlights why confusion continues to exist with so many staff positions involved.

While the DDD-contracted health plans include care coordination for DDD members who need behavioral health services, the identification of the need often comes from the member's service plan facilitated by DDD Support Coordinators. There is a failure on the part of DDD Support Coordinators to ask families to reach out to the health plans to better coordinate these services. The health plans themselves are also not reaching out to these members. Since the integration, the designation of responsibility for referring behavioral health services isn't clear between DDD and the health plans. It is the responsibility of DDD to ensure that sub-contracted services and supports meet their contractual requirements with AHCCCS.

In a recent situation involving DDD, after the fourth month of a nonverbal member being in crisis without behavioral health services, the family was told by an Adult Behavioral Health Advocate with DDD that "there are currently options available for the family that will take time and patience to achieve." This was due to counseling staffing shortages. However, the DDD Behavioral Health Advocate was not introduced into the situation until after four months of crises. The member's health plan was never involved. At the very least, members who frequently use behavioral health and crisis services should be engaged by their Support Coordinators during quarterly meetings to ensure the members are getting the services they need and future crises may be minimized. Additionally, Support Coordinators should be instructed to notify the Justice Liaison within a few hours when they learn a family has had an interaction with law enforcement, jails, or the judicial system. They should notify the Behavioral Health Administration if there was a behavioral health crisis to ensure there is no breakdown in communication.

(Note: In November 2021, DDD issued a policy clarification over the type of technical assistance the Behavioral Health Administration can provide to help Support Coordinators navigate the complex behavioral health system with their members. This technical assistance has been available since 2019. Due to the recent guidance, it is unclear if this clarification will improve service coordination.)

5. DDD-CONTRACTED PROVIDERS AND VENDORS REQUIRE ADDITIONAL GUIDANCE ON BEHAVIORAL HEALTH NEEDS OF ID/DD MEMBERS



- A. Training is needed for behavioral health service vendors on how to successfully accommodate individuals with ID/DD, including how to use Augmentative and Alternative Communication (AAC) devices.**
- B. DDD-contracted providers and vendors require additional training, resources, and funding to adequately serve people who have ID/DD and co-occurring mental health diagnoses.**

Background:

A. A mental health diagnosis is often overlooked in people with ID/DD. There is often a tendency to recognize only the developmental delay and attribute any behaviors to that condition. This phenomenon, known as overshadowing, blinds the clinician to the possibility a mental illness could be the cause of the behaviors for which the person is being referred. Moreover, standard clinical graduate programs and medical schools do not include dual diagnosis in their training curriculum.

In response, the network available to serve people with ID/DD who have behavioral health needs is limited. A recent 2021 [report](#) finds that these unmet mental health care needs especially harms children who have autism. They were less likely to participate in the community than their peers who had no unmet mental health needs. Peer Support Recovery Specialists are an inherent part of Arizona's behavioral health model, offering peer support from certified and trained individuals who themselves have been through recovery. Peer Supporters generally are provided to DDD members, but Peer Supporters who have ID/DD are not an option. These peers offer different lived experiences and can understand the unique needs of a member with I/DD, but peers with ID/DD are not included as part of DDD's integrated health service plans. Furthermore, agencies often cite a lack of available training on providing counseling services with this population as an issue to service provision. As a result, there is a very limited supply of providers that are trained to serve people with ID/DD. Of 146 agencies and counselors contacted, 26 confirmed they provide trauma counseling to members with ID/DD and accept AHCCCS. Most were in urban areas of the state.

It is also a struggle to find in-patient behavioral health hospitals in Arizona, especially ones that will take nonverbal patients with autism. In some cases, individuals have been relocated to other states to receive the care they need. T/RBHAs may also use their discretion regarding the extent of services they believe a member can receive, which may discriminate against the person with ID/DD. For example, a person with a disability was put on a call plan by the T/RBHA, restricting the number of times the person could call the crisis line. Behavioral health and correctional facility placements also discriminate against people who are nonverbal and use augmentative and alternative communication (AAC) devices. These devices are often confiscated and substituted with other devices the individual is not trained on, which is a civil rights violation.

Mental Health America released its 2022 report on the state of mental health care and ranked Arizona 49 out of 51 in the country for its high prevalence of youth mental illness and overall poor access to care. However, there has been progress in expanding the supply of children's crisis services. AHCCCS recently submitted a proposal to the Substance Abuse and Mental Health Services Administration (SAMHSA) to use funding through American Rescue Plan Allocation (ARPA) to increase their crisis service infrastructure to serve children. There have also been recent enhancements made to children's crisis services through Mercy Care in the Central Region of the state. These enhancements include the start of child and adolescent mobile crisis intervention services available 24

hours a day, 7 days a week with in-home supports in both the immediate crisis resolution, and coordination of ongoing supports through outpatient providers in the community. There are also three new children and adolescent crisis observation and stabilization programs launched in Maricopa County that are open 24 hours a day, 7 days a week.

B. Most providers and staff are unaware of the prevalence and symptoms of behavioral health issues in people with ID/DD. This knowledge gap can be partially attributed to long-standing stereotypes that people with ID/DD do not have the cognitive capability to experience mental illness symptoms. Research and studies have repeatedly debunked these myths. However, this information has not been effectively communicated to providers and the staff that provide daily support to these members. Ignorance of the commonality and signs associated with mental illness has created systemic gaps that fail to support members with dual diagnoses.

In response, there are minimal resources and guidelines issued to DDD-contracted providers to better serve this population, resulting in ill-prepared DDD providers and vendors. The absence of guidance manifests in gaps in knowledge and support that impact the quality of life for members with co-occurring conditions.

Among providers, there also remains unclear instruction of what to do when a member requires emergency psychiatric services. Insufficient guidance has resulted in a haphazard response to emergencies among providers, often involving law enforcement, crisis response teams inexperienced with ID/DD, and ineffectual services. Providers need to be better equipped with resources to expeditiously connect members with appropriate crisis services when the situation arises. DDD asserts that DDD teams can develop crisis plans for members. DDD Behavioral Health Administrators can collaborate with DDD-contracted health plans to better support individual members in crisis, yet providers are unaware of these options.

While DDD does provide regular “Developing Behavior Plans workshops,” providers maintain that provider and vendor training from DDD are inadequate. This impacts the DDD-required Behavior Treatment Plans (BTPs) drafted to address member behavioral health needs. BTPs are vital documents that can impact member rights, medication, and daily supports. They assist providers in: recognizing behavioral signs and symptoms; coordinating with clinical staff; and offering habilitation goals to support the development of positive replacement behaviors. BTPs also track a member’s progress with clinical intervention and medication monitoring by licensed clinicians.

DDD providers are responsible for writing BTPs for members living in their residential settings. However, this process illustrates a significant need for providers to be trained about psychiatric diagnoses and behavioral health systems. Currently, they lack adequate knowledge of the symptoms and treatment of psychiatric conditions. The resulting documents are not based on criteria outlined by DDD and may not reflect evidence-based practices for people with dual diagnoses. DDD has a Program Review Committee, supported by the clinical team in the DDD Behavioral Health Administration. This clinical

team includes three licensed behavior analysts, a licensed psychologist, and a psychiatrist. They can conduct second level reviews of plans when there are concerns regarding behavioral health needs and services. However, it is unclear if providers are aware of this level of support.

Deficient provider staffing also negatively impacts DDD-contracted services, specifically for members with complex behavioral needs. DDD providers are experiencing a staffing crisis due, in part, to the low reimbursement rates issued by the State of Arizona and the workforce shortage. Staff shortages and high turnover among providers cultivate unsafe conditions and supports. As a result, members with dual diagnoses are at a heightened risk of having their needs overlooked and neglected due to staffing concerns, thus requiring crisis intervention instead of consistent mental health management.

6. FAMILIES AND PEOPLE WITH ID/DD NEED EDUCATION ON NAVIGATING THE CRISIS/BEHAVIORAL HEALTH SYSTEM



A. Health plans, T/RBHAs, DDD, and law enforcement together need to educate members with ID/DD and their families on how to navigate the crisis response system, what to expect, and what they should do to better advocate for themselves.

B. AHCCCS' contractual requirements should mandate that individual health plan identification cards require a crisis phone number.

Background:

A. DDD states that it provides behavioral health advocates and complex care specialists statewide to assist members and families in navigating the behavioral health systems of care. However, many families are unaware of this resource. They do not understand how to navigate a confusing crisis system with unclear rules. They don't know that general on-going behavioral health services and crisis services are administered through different systems. Furthermore, general behavioral health services are not delivered by DDD; they are delivered by contractors with the health plans that contract with DDD. In this complicated web of agencies, plans, and vendors, it is no surprise that individuals, families, and the general public have no idea who is responsible for what service, what their expectations and timelines for services should be, and how to advocate for themselves effectively during a crisis.

To eliminate some of this confusion, there should be flyers created to help navigate the system during a crisis. Health plans should also educate families on their Justice Liaison positions. Families will then know who to call when contact with local law enforcement has been made. This call would ensure there is a connection made with DDD. Families could also notify their DDD Support Coordinators of interactions with law enforcement or crisis response when it occurs. This additional communication would help address some of the communication gaps that are occurring.

Sharing in law enforcement's frustration, families also don't understand the roles and responsibilities of law enforcement regarding behavioral health crises. Information and visualizations on how crisis response is supposed to work would be beneficial to not only family members, but all stakeholders who are involved in the crisis response system. It is also recommended that local police departments reach out to the ID/DD and behavioral health community to establish what their current protocols and limits are during mental health crises to help individuals and families set expectations and navigate the system more effectively.

B. While AHCCCS has information regarding crisis lines by county on their website, member and families are sometimes still unaware of where to call if their loved one is in crisis. Often families will just call 9-1-1. Including the crisis hotline number on member health plan cards, as well as the upcoming National Suicide Prevention Lifeline number 9-8-8, may redirect calls from police. Members may then be more likely to obtain services that are more appropriate to the situation.

7. IMPROVE TRAINING ON ID/DD FOR MEDICAL STUDENTS, FAMILY PRACTICE RESIDENTS, AND GENERAL PHYSICIANS



Both the physical and behavioral health needs of individuals with ID/DD need to be adequately addressed by the medical community

Background: When someone with ID/DD presents with behavioral difficulties, it can be challenging to determine the underlying cause. Because of their cognitive disabilities, individuals with ID/DD are less likely to have appropriate coping skills for a variety of stressors. Also, many people with ID/DD have limited verbal skills, so pain and discomfort caused by medical problems may be expressed as physical aggression. Physicians can provide better care by being trained in and considering these diagnostic challenges and gaps in services the ID/DD experiences.

A recent [Lancet study](#) finds Individuals with ID/DD are more likely to have ongoing untreated medical conditions that contribute to their crises. An abundance of [research](#) has also found that especially among individuals with autism, they are more likely to overuse emergency rooms due to inadequate primary care. They tend to wind up in emergency rooms when they are in crisis to get treated and stabilized for their mental health condition, not their underlying health conditions. They often don't see a doctor again until the next crisis. Some of these individuals live in group homes or have been admitted to a behavioral health hospital to address the crisis. Unless there is a family member or other advocate, often these individuals will not receive the appropriate medical care they need to identify any underlying medical conditions. To improve treatment and response, the crisis response system and medical community should focus on all necessary medical and behavioral needs of the individual to address the needs of the whole person and prevent future crises.

CONCLUSION

The primary theme resonating through each of these recommendations is the lack of education, training, and coordination between AHCCCS, DDD, the DDD-contracted health plans, the DDD vendors, the T/RBHAs, their providers, first responders, individuals and families. With so many stakeholders involved in events that can be viewed as life-saving or life-ending, it is imperative that immediate action is taken.

This report's recommendations are a start to truly integrate behavioral health and crisis services for people who have ID/DD. There should be required communication protocols established and monitored, benchmarks set in coordination with members and families, education for individuals and families on how to navigate the system, and training for the crisis response system as a whole on the needs of the ID/DD community. In addition, procedures and legislation involving police interaction and people with mental health issues, ID/DD and other disabilities need to be re-examined.

Moving forward, a group of stakeholders convened by the ADDPC will continue to meet to begin to address some of these gaps and corresponding recommendations. AHCCCS and DDD have already begun to prioritize these issues through grant requests and the provision of additional technical assistance. More may be accomplished as we seek to establish a behavioral health and crisis system that is inclusive of all, including people who are nonverbal and/or have ID/DD.

Summary of Recommendations

1. Require stronger accountability of crisis service providers
2. Monitor communication protocols
3. Training, resources, and potential legislative changes are needed for law enforcement
4. DDD Support Coordinators and health plans require additional training on behavioral health needs of the ID/DD community
5. DDD-contracted providers & vendors require additional guidance on behavioral health needs of ID/DD members
6. Families and people with ID/DD need education on navigating the crisis/behavioral health system
7. Improve training on ID/DD for medical students, family practice residents, and general physicians