ARIZONA
INDEPENDENT OVERSIGHT COMMITTEE

November 1, 2024

The Honorable Warren Petersen
President, Arizona State Senate
1700 West Washington Street
Phoenix, Arizona 85007

The Honorable Ben Toma
Speaker, Arizona House of Representatives
1700 West Washington Street
Phoenix, Arizona 85007

Dear President Petersen and Speaker Toma,

On behalf of the DDD District Central Independent Oversight Committee, please find the 2023-24 Annual Report that outlines our committee's activities and recommendations. The report was prepared in accordance with the requirements of A.R.S. § 41-3804(H).

Thank you for your continued support of the committee volunteers who are protecting our most vulnerable population: individuals with developmental disabilities/intellectual disabilities. We look forward to collaborating with you should the need arise for legislation that would best serve and protect these individuals.

We know we can make a difference in the lives of all who are impacted. However, there are times when our volunteer committees alone need the help of others to initiate change, and that begins with people such as yourselves.

Sincerely,
Lisa Ehlenberger
DDD Independent Oversight Committee, District Central, Chair

cc: Thomas "T.J." Shope, Senate Health and Human Services Committee
Carmen Heredia, Executive Deputy Director of Arizona Health Care Cost Containment System
Elizabeth Alvarado-Thornson, Executive Deputy Director of the Arizona Department of Administration
David Lujan, Cabinet Executive Officer (CEO) of the Arizona Department of Child Safety
Jennie Cunico, Cabinet Executive Officer of the Arizona Department of Health Services
Angie Rodgers, Executive Deputy Director of Arizona Department of Economic Security
Steve Montenegro, House of Representatives Health & Human Service Committee

Department of Economic Security
Division of Developmental Disabilities

DISTRICT CENTRAL
INDEPENDENT OVERSIGHT
COMMITTEE

2023-2024 ANNUAL REPORT

INTRODUCTION AND BACKGROUND

The Independent Oversight Committee (IOC), formerly the Human Rights Committees, supported by the Arizona Department of Economic Security (DES), were established into law under A.R.S. 41-3801 and functions as an independent advisory and oversight committee to the Division of Developmental Disabilities (DDD). Independent Oversight Committees (IOC) were established to promote and protect the rights of members with developmental disabilities who receive services from the Division of Developmental Disabilities.

In 2023/2024, District Central (DC) served 9,486 DDD members. The DC IOC monthly meetings have been held virtually since 2020 and currently meets on the fourth Friday of the month for approximately two hours. The District Central Committee met 10 times this year. The DC IOC also developed several subcommittees this year, which met on multiple occasions, resulting in regular meeting actions/motions and recommendations.

RESPONSIBILITIES AND DUTIES OF THE INDEPENDENT OVERSIGHT COMMITTEES

The Independent Oversight Committees (IOC) are made up of dedicated volunteers who donate their time to serve and support the rights of DDD members within their districts and statewide.

The IOC operates under the Open Meeting Laws of Arizona and follows specific IOC Guidelines created by their district. In addition, the committee provides independent oversight, reviews research, and makes recommendations to the Department of Developmental Disabilities. The committee reviews reported incidents, including Physical Abuse, Sexual Abuse and Other Abuse, Neglect, Accidental Injury, Missing Clients, Emergency Measures, Human Rights Violations, Medication Errors, Death, Suicide, Hospitalization, Theft, Other Behaviors, Legal and Property Destruction. The IOC members also sit on Program Review Committees (PRC) reviewing and making recommended changes within Behavior Treatment Plans (BTPs) and Person-Centered Support Plans (PCSP), which include, yet are not limited to, a review of teaching methods, data, rights restrictions, spending plans, and medications.

DISTRICT CENTRAL
Independent Oversight Committee
Membership

Lisa Ehlenberger, Chairperson, Family Member/School Psychologist/Advocate, inception 2010

Eva Hamant, Parent/Advocate, inception 1998

Mandy Harman, Member/Special & General Education, inception 2015

Carolyn Wilmer, Family Member/Health Care/Early Childhood Education, inception 2022

Amber Stock, Parent/Special Education, inception 2024

Michael Johnson, Behavioral Health Coach/Service Provider, inception 2024

Megan McCarthy, Resident Psychologist/Advocate, inception 2024

Stephanie Reynolds, Clinical Psychologist/School Psychologist/Advocate, inception 2024

Heather Marlowe, Family Support Partner/Advocate/Parent, inception 2024

There continues to be a recruiting and retention challenge for volunteers to the DDD Independent Oversight Committees across the state. District Central IOC had 6 Members on July 1st, 2023. In addition to members Linda Mecham, past chair, and Debbie Stapley, past vice-chair, retirement in January of 2024, Eduarda Yates, another longstanding IOC volunteer, passed away in August of 2023.

Our goal remains to bring in new volunteers who are dedicated to a possible lifelong membership. This is important to the committee as policy and system changes are inevitable. The consistency with volunteer committee members allows for a historical perspective. This enhances our ability to advocate for DDD members throughout their lifespan.

By law, the District Central Independent Oversight Committee reviews all incidents of abuse, neglect, and human rights violations of the members who reside in Central Arizona. Revised Statute 41-3801 defines and explains the duties of the Independent Oversight Committees:

A. The independent oversight committee on persons with developmental disabilities is established in the Arizona Department of Administration to promote the rights of clients receiving developmental disabilities services pursuant to Title 36, chapter 5.1.
B. The committee shall be organized pursuant to this section and the requirements of section 41-3804.
C. The director of the department may establish additional committees for each district office established pursuant to section 41-1961 or to oversee the activities of any service provider.
D. Each independent oversight committee established pursuant to this section shall consist of at least seven and not more than fifteen members appointed by the director of the department with expertise in at least one of the following areas:

1. **Psychology.**
2. **Law.**
3. **Medicine.**
4. **Education.**
5. **Special education.**
6. **Social work.**
7. **Criminal justice.**

E. Each independent oversight committee shall include at least two parents of children who receive services from the division of developmental disabilities.
F. The division of developmental disabilities shall provide to each independent oversight committee information regarding incidents of:

1. **Possible abuse or neglect or violations of rights.**
2. **Physical abuse, sexual abuse and other abuse.**
3. **Accidental injury.**
4. **Missing clients.**
5. **Behavioral emergency measures.**
6. **Medication errors, including theft of medication or missing medication.**
7. **Death.**
8. **Suicide attempts.**
9. **Hospitalizations.**
10. **Incarcerations.**
11. **Theft of client property or money.**
12. **Property destruction.**

G. The Division of Developmental Disabilities in the Department of Economic Security must allow the Independent Oversight Committee on persons with developmental disabilities thirty days to review new policies and major policy changes before the Division submits the policies or changes for Public Comment.

INCIDENT REPORTS

There were **7,897 Incident Reports** provided to the District Central IOC from July 1st, 2023, to June 30th, 2024. The number of Members served in District Central was **9,486,** with **56,454** individuals enrolled with DDD as of June 30, 2024. (*data taken from the report by the Division of Developmental Disabilities, titled "Member Demographics as of June 30, 2024". Source: Focus Management Reports Mgmt. 0010 through Mgmt. 0060)

District Central IOC receives all Incident Reports by accessing a secure Google Drive. This platform allows the volunteer committee members to access all the Incident Reports at any time and allows an immediate comment or question to be added to the IRs. **Previously, the IOC had access to more detailed information in Incident Reports; over the past years, the reports were increasingly redacted, making it difficult to provide general oversight.** However, one of the issues with the incident reports is that the Division was not getting all of the information from the vendors/agencies. With the support of the DDD quality management unit, this issue has lessened, and the IOC's responses to the IR inquiries have also become more detailed and relevant to the initial questions.

DDD has discussed an AHCCCS portal, which IOC members will eventually be able to use to review incident reports. The District Central IOC is looking forward to having access to this portal, which is projected to allow IOC members to track and trend confidential redacted Incident Reports on a micro level, thus providing increased oversight on DDD member-specific issues/concerns.

BEHAVIOR PLANS

From July 1, 2023, to June 30th, 2024, **478 Behavior Treatment Plans/Person-Centered Planning Documents** were reviewed in District Central this fiscal year. The committee's goal is to continue reviewing every Behavior Plan in District Central.

IOC District Central Committee members Linda Mecham, Carolyn Wilmer, Lisa Ehlenberger, and Amber Stock participated in these reviews. They provided dedicated oversight/recommendations for the DDD members' Behavior Treatment Plans and Person-Centered Support Plans during the Program Review Committee (PRC) meetings in 2023/2024.

DISTRICT CENTRAL INDEPENDENT OVERSIGHT COMMITTEE VOLUNTEER HOURS AND TRAININGS

The District Central IOC volunteered more than 500 hours in 2023/2024. This year, the IOC was informed of a new annual training required, LAW 2000 Standards of Conduct, of which our volunteer members will continue to do so. ADOA/DDD also implements an "onboarding" training for IOC members. In addition, several of our committee members are taking advantage of the many trainings the Division offers online, such as Article 9, as well as some in-person trainings that have become available. IOC members also participated in several presentations, including a crisis intervention presentation, & peer and family support.

TOPICS OF DISCUSSION AND ACTION BY DDD DISTRICT CENTRAL IOC IN THE 2023/2024 FISCAL YEAR

POLICY EARLY NOTIFICATION

This year, more than **150 Policy Notifications** were sent out.

When the Policies were open for review, the DC IOC made motions for recommendations/comments on several early notification policies, including policies related to services in behavioral-supported group homes, BTP implementation, second-generation medication/metabolic panel, behavior modification medications, emergency measures, and restitution/restricted techniques. In addition, members of the DC IOC commented on many of these policies as individuals.

ARIZONA STATE HOSPITAL (ASH), BEHAVIORAL HEALTH HOSPITALIZATIONS, AND BEHAVIORAL HEALTH GROUP HOMES FOR DDD INDIVIDUALS

Starting in July 2023, DC IOC noticed that DDD members in ASH were experiencing an unusual number of instances where physical and mechanical restraints were used. These DDD individuals may have been at ASH for 5-10 years, but we have not been able to confirm the length of their time at ASH. We were informed that they are probably not eligible for release to a facility outside of ASH. We found AZ code 9-21-204 in August 2023 and formed a subcommittee to investigate the issue. We requested that DDD follow up with ASH about one member and how ASH was implementing AZ 9-21-204 concerning Seclusion and restraint for that member. While IOC was not happy with the response, ASH worked with that member to reduce or eliminate the use of physical and mechanical restraints. The other DDD members also seemed to have their instances of physical and mechanical restraint reduced or eliminated.

Hopefully, ASH will continue to work on positive behavior support for our DDD members.

Upon these several concerns, District Central developed a subcommittee. The following questions were submitted in January 2024, and responses are below in red:

1. Do UHC and Mercy Care have their own QMU or a shared QMU for DDD members while in the behavior health hospitals? If so, are they required to share their information with DDD's QMU?

a. Do they share their seclusion and restraint incidents with DDD's QMU per SAR's DDD policy 962? If not, why not since the DDD policy includes all members? Do the behavior health hospitals for UHC and Mercy Care follow AZ Code 9-21-204? **

Response: The Division's subcontracted health plans have their own Quality Management Units (QMU); which operate independently of the Division's QMU. The health plans are required to submit their Incident, Accident, Death (IAD), Internal Referrals (IRF), Quality of Care (QOC), and Seclusion and Restraints (SAR) within the

AHCCCS QM Portal. The Division oversees and monitors the health plan submissions through the AHCCCS QM Portal.

Yes, the Division's subcontracted health plans are required to submit SAR according to AMPM 962 and Division AdSS Medical Policy 962. Yes, the inpatient behavioral health facilities are required to comply with A.A.C. R9-21-204.

2. Per an earlier ASH report/response indicating that an ASH monthly report of all seclusion and restraint (S&R) events involving DDD members are sent to DDD's QMU. If this is a separate report (not included in IR's), the IOC would like a copy included for their review prior to each IOC meeting. Does this monthly report include prior redirection, antecedents, and precursors, as well as other least restrictive measures used prior to restraint (AZ Code 9-21-204)?

Response: The Division does receive monthly SAR reports from ASH, which, in turn, are forwarded to the IOC. The reports only provide a high-level summary of the SAR event and does not include the detailed information such as prior redirection, antecedents, and precursors, or other least restrictive measures used prior to the restraint. The Division's QMU does receive reported incidents from ASH, including SAR events.

3. How does DDD's QMU track and trend the SAR's quarterly report (from DDD members, including the members at ASH) that is sent to the QM/PI Committee? And what do they do with those reports? The IOC would like a copy of the quarterly reports as well as the QM/PI committee's recommendations.

Response:
The Division does not receive or produce a quarterly report for SARs. Per AMPM 962 and Division AdSS Medical Policy 962, requires our subcontracted health plans to enter all SARs into the AHCCCS QM Portal. The Division provides monitoring and oversight of submitted SARs through the AHCCCS QM Portal. The Division reviews SAR data during the QM Subcommittee and would bring any identified trends to the QM/PI Committee for review; as applicable.

4. What are the protocols for UHC and Mercy Care when the group home or guardian is not available/refuses to pick up a DDD member being released? Who is accountable for discharge procedures/guardian &/or group home education on discharge instructions?

Response:
The discharging facility should provide each member with discharge instructions for follow up appointments, instructions for care guidelines and a medication list. Support Coordination should be responsible in the discharge planning team meeting to discuss changes to the members plan of care. Group homes should have policies in place for medication reconciliation when member returns post discharge.

5. Are the behavior health hospitals having a 72-hour post release meeting? Is the support coordinator always invited?

Response:
No, they do not have a 72 post-release. Crisis will have a 24 hour post discharge follow-up. DDD will schedule a CFT or ART to check in with the team post discharge

6. Does DDD pay for their members while in UHC and Mercy Care behavioral health hospitals? Do UHC and Mercy Care follow article 9 on DDD members while in the behavioral health hospitals? If so, who trains the staff on Article 9?

Response: Every DDD LTC has either UHCCP, Mercy Care, or Tribal Health Plans which have a behavioral health benefit that covers behavioral inpatient hospitalizations. Hospitals where DDD members are admitted are not required to follow Article 9.

Regarding the Behavioral Health Group Homes, the IOC discussed concerns with the enhanced ratio DDD members and the lack of day programs available, which may increase social isolation. DDD informed us that the Division is continuing to work on implementing a new service around housing for members who have complex needs and are dually diagnosed. The initial goal is to open at least ten group homes around the state to accommodate those members in a community-based setting and provide opportunities for successful living. In addition, DDD shared that the "DDD member would not only have their person-centered service planning meeting with DDD but there would either be like a child and family team or an adult recovery team meeting with Behavioral Health that we work with collaboratively."

The IOC will continue to monitor Seclusion and Restraint, the development of behavioral health group homes for DDD dually diagnosed individuals, the quality of care in behavioral inpatient hospitals, and crisis care coordination.

MEDICAL/DEATHS/MORTALITY REVIEW QUESTIONS

The mortality review process has been discussed at several DC IOC meetings this past year and in years past.

The DC IOC has been developing questions directed to DDD. We are interested in having DDD help us understand the mortality review process. We discussed that it would be helpful if we could have the relative employees/departments from DDD come to our meeting with a flow chart of the mortality review process and the quality-of-care concerns flow-charted as well.

We also discussed wanting to receive the top 10 causes of death in DDD members and a discussion of the five fatal preventable conditions. The "Fatal Five" (described in DES/DDD Medical Manual 6002M) is a group of preventable conditions that are often fatal for people with intellectual and developmental disabilities. They are:

- Aspiration
- Bowel obstruction
- Gastroesophageal reflux
- Dehydration
- Seizures

We have discussed how Person-Centered Service Plans (PCSP) can better address these conditions. We would also like more clarification on how unexpected deaths are handled differently from expected deaths.

Because one of the many categories of Incident Reports that we review is “Death,” the District Central IOC continues to be interested in learning more about mortality in DDD members. In the previous year, 22/23, we learned that about 10% of natural deaths can be classified as unexpected in the general population. [This estimate is based on the Sudden Unexpected Death in North Carolina (SUDDEN) project (https://openheart.bmj.com/content/3/1/e000321).] Unexpected vs. Expected Deaths in DDD Members

For DDD members, approximately 90% of deaths are classified as Unexpected Deaths. The definition of Unexpected Deaths is broader in the DDD population than in the *SUDDEN* project. The *SUDDEN* project includes only unexpected deaths from natural causes. The DDD definition includes unexpected deaths from all causes: “Unexpected Death means a sudden death and may include motor vehicle accidents, suicides, accidental drug overdoses, homicides, acute myocardial infarction or strokes, trauma, sudden deaths from undiagnosed conditions, or generic medical conditions that progress to rapid deterioration.” Expected Deaths, about 10% of DDD member deaths are defined as “natural death, and may include deaths from long-standing, progressive medical conditions or age-related conditions.” Most expected deaths occur in hospice care.

DDD members are at higher risk of unexpected death than the general population: they have a higher rate of multiple chronic health conditions and are often on multiple medications for medical and behavioral health issues. The term “polypharmacy” is often used to describe medical care involving multiple medications. There are a variety of definitions of polypharmacy, but the most common is taking 5 or more medications each day (https://www.webmd.com/drug-medication/what-is-polypharmacy). Polypharmacy, even when necessary and unavoidable, has risks. As the number of medications increases, there is a higher likelihood of side effects, drug interactions, and medication errors.

Because DDD members may not report side effects reliably, problems from polypharmacy may be missed.

As a result of the review of the “Death” Incident Reports and our findings thus far, we will continue to review and report on the policies and protocols relating to deaths of DDD Members as outlined in DES/DDD Medical Manual 6002-F Investigative Process, 6002-M Mortality Review Process, 960 Quality of Care Concerns, and 961 Incident, Accident, and Death Reporting. Specific topics are as follows:

1. Clarification of the quality-of-care concerns and mortality review processes is described in 6002-M and 960, respectively.
2. Current data on the top 10 causes of death in DDD members.
3. Discussion of the “Fatal Five” preventable conditions. How can these conditions be better addressed in the Person-Centered Service Plans (PCSPs)?
4. How are unexpected deaths handled differently from expected deaths?

5. Clarification on the record review required after death: The committee was told that all deaths require a record review 90 days after death. However, the 90-day requirement isn't included in 6002-M or any other policies listed above.

In addition, we would like to understand when death certificate information/autopsy results are used in the QOC concerns and mortality review processes.

We would like clarification and a better understanding of the record review required after death, and we will continue to develop inquiries surrounding this subject.

ARTICLE 9

Article 9 has been a topic of conversation for the IOCs for several years. In 2023, changes to the Article were presented to the Governor's Regulatory Review Counsel (GRRC). We were disappointed with how we found out that Article 9 had been submitted to GRRC. We assumed that IOC could review it one final time before the submission. In 2023, when asked in a Statewide IOC meeting what the status was for Article 9, we were surprised to learn from Mr. Garcia-Ramadan that it had already been submitted to GRRC. He told us he would let us know when it would come up on the GRRC Calendar for final review. Our committee and a few other individuals, providers, and IOC members from District West found the submitted Article 9 on the Secretary of State's website. We saw many issues with which we disagreed, so we determined to determine when it would come before GRRC. Believing very firmly that it did not represent the original intent of Article 9, nor was it in the best interests of the Individuals served by DDD, not to mention the many inconsistencies contained therein, we prepared and delivered our specific concerns to GRRC. DDD had pulled Article 9 from the GRRC calendar the following week.

We understand that DDD would like to change/revise Article 9, and we look forward to a more open dialogue, open participation, and one single committee, not internal and external stakeholders making suggestions.

We look forward to seeing the final document BEFORE it is submitted to GRRC. The IOCs are statutorily tasked with defending the Individuals served by DDD and ensuring that their rights, per Article 9, are not violated and that they are treated with respect and dignity in all aspects of their lives.

RESIDENTIAL BILLING ERRORS

DISTRICT CENTRAL HISTORY REGARDING RESIDENTIAL BILLING PROCESS

For several years, the DDD District Central Independent Oversight Committee has been aware of a consistent issue related to residential billing errors. A bill may represent an amount due; the following month would be completely different. Sometimes, the amount is a credit, and nothing is due. We have heard stories from families who have not paid anything, per the instructions on the bill, and then presented with a balance due of several thousand dollars when the previous month indicated a credit, which may create a real hardship for the family or the member who the Division serves.

We formally asked through MOTION in 2023 what the plans are and when they will be implemented for reviewing the DDD residential billing process, correcting the systemic error in billing calculations, and ensuring more transparency in the Member's residential bill to achieve a correct monthly statement for the Members and confidence in the residential billing system. ***See historical information below.***

As a result, the bill passed in the Senate in the Fall of the 2023 legislative session but did not move forward in the House. We continue to have concerns regarding billing errors.

The IOC Committee Members, as parents/guardians of individuals served by the Division and as representatives of so many families/representative payees who rely on accurate billing to have a basic budget, continue to believe that a complete audit of the billing process and system is needed, as well as expectations that an accurate monthly residential bill will be sent.

An additional continued consequence of this incorrect billing is that the DDD Member's AHCCCS/ALTHCS eligibility may also be at risk, through no fault of their own, because their bank account balance is over the allowable $2000.00 limit, per AHCCCS/ALTHCS/CMS rules.

Historical information regarding residential billing:

DDD RESPONSE TO OUR MOTION:

"The Division is currently updating DDD Operations Policy 4002, Client Billing. We expect to submit to public comment in February 2023. This policy indicates the financial responsibility for the cost of care portion based on DDD eligibility. (ALTCS and non-ALTCS members). The Division utilizes the Federal Poverty Guidelines to calculate the monthly statements for members. This amount can change based on the member's income or benefits the Member receives, including Social Security, Veteran's, and Railroad Retirement benefits. Additionally, new benefits rates are updated yearly, typically taking 2-3 months to reflect in the monthly statements.

"For instance, Social Security benefits and Supplemental Security Income (SSI) payments increased by 8.7% in January 2023, therefore by March all monthly statements will reflect this change. In addition, it is essential members/responsible persons provide recent tax information annually. The Responsible Person or Representative Payee may request a financial review of the Member's Cost of Care Portion payment amount, by requesting in writing anytime. The Responsible Person or Representative Payee shall submit the request via email to dddrevenuedesk@azdes.gov and include recent tax forms."

Upon reviewing DDD's response, the District Central IOC felt our questions were unanswered. We know what the policies are. Per our motion, the problem is the systemic data system that consistently sends incorrect monthly statements regarding residential billing. We followed up on our motion by requesting an in-person meeting with DDD Asst. Dir. Mr. Garcia-Ramadan. Larry Allen, our ADOA liaison, requested the meeting for us, stating that our concerns are not with regards to policy or an individual, but rather, "Specifically, the detail they are concerned with is that the monthly billing

cycle is systemically not working due to showing wrong amounts due for the DDD member."

Past IOC Member Carol McNulty, IOC Vice-Chair Debbie Stapley, and Chair Linda Mecham met with Mr. Garcia-Ramadan and Larry Allen in 2023. After the issues were explained along with specific examples, Mr. Garcia-Ramadan understood that he needed to go to DES to get the information we were requesting and also to determine if and when the changes could be made to the data system so that he could have correct monthly residential statements.

We did have a follow-up conversation with Mr. Garcia-Ramadan. He stated that upon meeting with DES, it was determined that fixing the residential billing problems "***would take years to fix this issue***."

"ABUSE AND NEGLECT" CURRICULUM FOR DDD INDIVIDUALS

This curriculum was mandated by Governor Doug Ducey when the "Hacienda Incident" occurred. (A young lady was raped, and a pregnancy resulted.) District Central IOC has no issues with the curriculum for the Provider community. Our issue was with the curriculum that was developed for DDD Individuals. We felt it was highly explicit and generally, above the ability of DDD Individuals to understand. Additionally, we were concerned about the possible PTSD effects the training could have on individuals who had experienced some type of abuse and/or neglect and the need to have a professional presenting the curriculum who is licensed/trained in trauma-informed care, who can recognize and deal with possible side effects of this training. We were also concerned with the training being done in a group setting when it should be highly individualized, especially if it triggers behaviors that may be upsetting to others in a group setting, which could set up a snowball effect of behaviors by other individuals participating in the presentation.

The annual report for the past two years outlined our concerns. A DDD representative stated that the plan is to send a Request for Information to the public, with proposals out by June 2023. We asked what was happening with the curriculum in the meantime. We were told it was optional and that DDD was not seeing many individuals using it.

Again, we strongly suggest that there needs to be follow-up with training for when the curriculum triggers unwanted behaviors or responses and is interpreted by someone highly trained with the different I/DD learning styles. DDD stated that the IOCs would be included in the workshop and development of the new curriculum.

We continue to not know the status of the Abuse and Neglect Curriculum at this time.

PROGRAM REVIEW COMMITTEE, BEHAVIOR TREATMENT PLANS, AND PERSON-CENTERED SERVICE PLAN

One of the IOC's responsibilities is participating in the Program Review Committee. This committee reviews Behavior Treatment Plans (BTP), part of the Person-Centered Service Plan (PCSP). The PCSP was adopted in the past, following adoption from the requirements of AHCCCS, and should contain the information in the previous service document, the Individual Service Plan (ISP). While reviewing the BTP, looking for possible violations of Article 9/rights restrictions, we also review the PCSP. Upon this review, we continue to notice that there are consistent errors &/or items missing, even though they should be included:

Through PRC, IOC noticed that data was missing from PSCP and that the BTPs were out of date. In addition, when reading closed IRs, QMU frequently discovers that BTPs are out of date.

Historical Background;
Accurate diagnoses and communication functioning;
Appropriate Target Behaviors, Individual Goals, Outcomes, and Methodologies;
Rights Restrictions;
Consistency of medications throughout the document;
Spending Plan;
Current Medication Review/AIMS testing results;
Signatures with Dates indicate Informed Consent AND Team Agreement (No contract is complete without signatures.)

DDD continues to implement training on how the BTP and PCSP documents must be completed and their importance in the ongoing record-keeping for individuals served by the Division. In addition, they have created a new template designed to help consistency among Behavior Plan writers, and they have added an additional PRC team to assist with the many incoming BTPs. The DC IOC also discussed that it would like to include the past 90 days of IRs with each BTP submittal.

ELECTRO-CONVULSIVE THERAPY and DDD INDIVIDUALS

The Division of Developmental Disabilities met with District Central IOC in April 2023 to discuss using Electro-Convulsive Therapy (ECT).

We are including this in our current annual report (2023/2024) because it is an ongoing concern.

Leah Gibbs presented the following information (per the transcribed minutes in April 2023): "Historically, it was known as electric shock therapy. Governmental regulatory involvement in the use of ECT has historically been prohibited for various reasons, including patient advocacy and prior abuse by the medical community of people with developmental disabilities. This is contributed to heavy regulation, by state administrative codes and regulations.

"We're here today to propose consideration of amending Arizona Revised Statute 36-561. Through legal consultation, it was reported that the original language of the statute passed in 1978 and that this legislation was passed in a much larger piece of legislation regarding individuals with developmental disabilities. The division believes

the statute, as it reads, does not reflect current practice. And was created to protect vulnerable populations from overuse, misuse, and abuse of non-evidence-based medical practices. The division also believes the current statute has not been taken into consideration. Based on research and best evidence-based practices, the current clinical indications are considering proposing to amend the statute to present it to the state legislature for approval. Today, electroconvulsive therapy is permitted in certain circumstances and is a covered service under AHCCCS and our subcontracted health plans, United Healthcare Community Plan and Mercy Care Plan.

"Arizona Revised Statute 36-561 is titled "Prohibiting, Certain Treatment, and Drugs, Use of Aversive Stimuli." The language in the statute reads. '*No psychosurgery, insulin shock or electric shock treatment, or experimental drugs shall be administered by the department to any client. Nor shall the department license, approve, or support any program or service that uses such treatment or drugs. The Department shall adopt rules and regulations specifying. The immersive stimuli used for any developmental disabilities program or service provided directed by licensed or supervised by or supported by the department. Copies of such rules and regulations shall be made available to all parents, guardians, applicants and clients participating in placement evaluations. The Department shall provide at least 60 days' notice to all responsible persons or to implementing any modifications to such rules or regulations. No aversive stimuli shall be used, or permitted by the Department in any such program or service except in accordance with the adopted rules and regulations and the client's individual program plan'*.

"Electroconvulsive therapy today is a medical treatment completed under anesthesia by a team of trained. Medical professionals. When least restrictive options such as therapies and medications have been intolerable or ineffective. It is also used for people who require a rapid response because of the severity of a condition.

"Electroconvulsive therapy today is much different than it has been in the distant past and is highly regulated and is effective for many psychiatric disorders. For example, People who may be diagnosed with severe depression, especially when accompanied by a detachment from reality, psychosis. Or a desire to commit suicide or the refusal to eat. Another condition would be catatonia. A condition in which a person can become increasingly agitated or unresponsive. Another being treatment resistant. Bipolar depression and mania and another being schizophrenia. In fact, the first use of electroconvulsive therapy in psychiatry was in the treatment of schizophrenia. Based on clinical observation of persons with epilepsy and schizophrenia also often had an improvement in symptom severity, following a spontaneous seizure treatment guidelines have been developed by the American Psychiatric Association related to its use and these guidelines are supported by the Joint Commission on Accreditation for Health Care Organizations. Also known as JACO. A United states-based nonprofit, tax-exempt organization that accredits US healthcare organizations and programs. The international branch accredits medical services around the world.

"So today the Division has a proposed position. In that position, despite the potential revision, the Division still maintains its position, which is consistent with Article 9 that electroconvulsive therapy cannot be used as abuse, as an aversive intervention, or as an intent to cause physical, or psychological pain, or harm to a member, or as a form of punishment, because of the consequence of the behavior. DDD would like to consider the possibility of using electroconvulsive therapy when clinically indicated and least restrictive treatment options have been exhausted. I have a brief little summary. I'd like to share: "Today electroconvulsive therapy is currently a Medicaid covered service that is evidence-based and is no longer performed in the manner it was used in the past. Currently DDD members who have exhausted all other options are unable to

access this option as a form of treatment. Other people in the state of Arizona with these types of psychiatric disorders have access to this treatment. However, this law restricts this option for people with developmental disabilities." (End of transcribed minutes, from April 2023 as presented by Leah Gibbs)

DDD has since met with the IOC Chairs and other interested IOC members. In this meeting, it was discussed whether the IOC's scope of authority includes ECT Review/Approval and whether or not the IOC should be able to approve this medical procedure for the Individual. If a doctor requests/authorizes this procedure, the IOCs are not in a position to determine medically if this is correct.

Our <u>PRIMARY</u> concern is whether this Individual's rights are being violated, whether through Informed Consent and the following of all procedures that would safeguard the Individual or possible overuse or inappropriate use of this procedure.

Therefore, the questions/concerns from District Central IOC remain the same: DDD has not provided us with any data regarding ECT, such as success rates and long—and short-term side effects. Is ECT being used as a less-expensive procedure because other options are more expensive?

We still believe that IF this AZ Statute is changed, it MUST contain wording to the effect that a doctor's prescription must be presented, how many times the procedure has been used on the individual (to avoid possible overuse), results of previous procedures, and IOC review and approval that all policies (which DDD has not formulated, but which must protect the Individual) have been followed.

If per the IOC statute [A.R.S. § 41-3801], it is beyond our scope of authority to review this medical procedure, we would request that in addition to the change in legislation for the use of ECT for DDD members, an addition be added [A.R.S. § 41-3801], which will include our ability to review this possible use/misuse of ECT.

<u>MONITORING OF DDD GROUP HOMES AND INTERMEDIATE CARE FACILITIES</u>

An issue that comes up consistently for District Central IOC is the monitoring of Group Homes. We invited DDD to comment on this issue, especially regarding prior notification of monitoring being announced rather than unannounced visits, so DDD can see the Group Home on any given day as it is in a typical daily situation. DDD informed us that prior notification is not provided for monitoring. However, because monitoring is an annual occurrence, agencies can generally determine when the monitoring will occur and prepare for that. If there are concerns, an Incident Report can be submitted, and DDD can investigate.

District Central knows this is an ongoing concern and should be elevated to ensure that safety, security, health, and appropriate staffing and record keeping are current and in the interest of all individuals living in the home. In addition, early notification policies received this year appear to address additional requirements promoting the safety, security, and health of DDD members residing in group homes and Intermediate Care Facilities. We will continue to monitor these concerns.

ADDITIONAL ONGOING DISCUSSIONS

Many of the above concerns are ongoing issues. Because of their importance, the DC IOC is committed to continuing to pursue and take action as necessary to protect the rights of individuals with developmental disabilities related to these subjects.

In addition to the detailed subjects above, the DC IOC has begun additional discussions that will be a part of the 2024/2025 Annual Report, including, yet not limited to the following:

Department of Child Safety and care of DDD members

Behavioral Health Facilities and care of DDD members (minors and adults)

Crisis response/Mental Health and DDD members

Funding for DDD

Agency Trainings and monitoring/staffing issues

Parents as paid providers & assessment tool

MEMBERSHIP OF DISTRICT CENTRAL I.O.C.

The past several years has been difficult for the membership of the District Central IOC.

Multiple members either passed away or retired from the committee. These individuals were lifelong advocates for DDD members.

I will never forget their passion and dedication to protecting the human rights of our most vulnerable population, individuals who may not always be understood, who may not always be able to self-advocate, who may need the extra care and attention from the people around them…and from the people who create policies.

These past IOC members include Karen Van Epps, passed away in 2022, Sherri Howard-Wilhelmi, passed away in 2023, Eduarda Yates, passed away in 2023, Carol McNulty retired in April 2023, Linda Mecham and Debbie Stapley retired in January 2024. Each one of these amazing volunteers are greatly missed in our meetings.

Thankfully, we continue to be able to call upon Carol McNulty, my aunt, who was a committee member from its inception and retired in 2023. Her recall of the historical rationale behind so many of the rules, statutes, Article 9, and implicit understanding of DDD is vital to the IOC, especially in recent years as changes are taking place in the DDD world. She has handed me a plethora of historical documents that assist in recalling significant facts/issues faced throughout past generations. We also continue to call upon Linda Mecham, who has guided me through this first year of being the IOC chair and this annual report.

In addition, we have the dedicated Eva Hamant, who diligently continues to be an IOC member (since 1998) and advocates for all DDD members. Mandy Harman and Carolyn

Wilmer continue to volunteer and are assets to this committee. We, as a committee, are looking forward to collaborating with our newest members, who began this year: Amber Stock, Michael Johnson, Megan McCarthy, Stephanie Reynolds, and Heather Marlowe. I would not be able to fulfill this role without each one of them.

Our goal remains to bring in new volunteers who are dedicated to a possible lifelong membership. This is important to the committee as policy and system changes are inevitable. The consistency with volunteer committee members allows for a historical perspective. This enhances our ability to advocate for DDD members throughout their lifespan.

We are always looking to improve our committee membership, and have called upon the DDD volunteer unit to help us. **Fortunately, with these efforts from DDD and the current DC IOC volunteer members, we did obtain 5 new members thus far in 2024.** As we sit in different meetings, converse with parents, and professionals, we invite them to join. We are hopeful and remain positive, and as always, we remain dedicated to defending and protecting the rights of those Individuals served by the Division of Developmental Disabilities.

If you wish to discuss this report's contents, please do not hesitate to contact me at + 1 949 351 1849, or natrllis@yahoo.com.

Respectfully submitted,

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