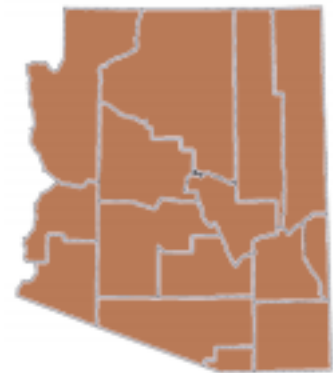


# DDD DISTRICT EAST INDEPENDENT OVERSIGHT COMMITTEE

Division of Developmental Disabilities

## 2020-21 ANNUAL REPORT



Arizona Department of Economic Security

Independent Oversight Committee  
DISTRICT EAST  
July 1, 2020-June 30, 2021  
ANNUAL REPORT

Division of Developmental Disabilities

**Prepared by Suzanne Hessman Chairperson  
on behalf of the Independent Oversight Committee District East  
Independent Oversight Committee Function**

Independent Oversight Committees (IOCs) are required by ARS 41-3801 and 41-3804 and function as an independent advisory and oversight committee for members being served by the Arizona Division of Developmental Disabilities. District East serves the southeastern portion of Maricopa County, southern portion of Gila County and all of Pinal County, including the Arizona Training Program at Coolidge.

Each committee shall provide independent oversight to:

- Ensure that the rights of clients are protected.
- Review incidents of possible abuse, neglect, or denial of a client's rights.
- Make recommendations to the appropriate department director and the legislature regarding laws, rules, policies, procedures, and practices to ensure the protection of the rights of clients receiving behavioral health and developmental disability services.
- Each committee shall issue an annual report of its activities and recommendations for changes to the ADOA Director, the Director of the Department of Economic Security, the President of the Senate, the Speaker of the House of Representatives, the Chairpersons of the Senate health and human services committee and the House of Representatives health committee, or their successor committees.
- Approve the use of sedation for medical and dental procedures as needed for members living at ATPC on an annual basis.

Our primary efforts have been focused on reviewing Incident Reports given to us by DDD Quality Management and Behavior Treatment Plans submitted to DDD, that have been approved by Program Review Committee for DDD, for individuals who live in a DDD residential setting and are taking any medication(s) that assist in behavior modification.

We look at data trends regarding providers and the number of incidents they report in a month, we also look at individual members and the number of incidents they have in a month to see what resources need to be extended to them or action taken by the team to improve the quality of life.

This year we have also changed our focus to actively advocating for changes to policy and legislation to improve the quality of life of our members.

## **Membership**

Suzanne Hessman – Chairperson – Parent/Advocate, Realtor

Sarah McGovern – Vice-Chairperson - Parent

Susan Kingsbury – Counselor

Elizabeth Bird – Parent

Kin Counts – parent

Amanda Godek – Article 9 trainer

Tonia Schultz – ATPC representative (non-voting)

Per ARS 41-3801 our committee is to be comprised of at least seven and no more than fifteen members with members having expertise in the following areas: psychology, law, medicine, education, special education, social work, criminal justice and at least two parents of children who receive services from DDD.

Our committee is made up of volunteers who mostly are employed full time, primarily parents who have family members receiving a variety of services from DDD. Dedicating the time necessary to participate on the committee has been a strain at times on our members; however, they chose to serve regardless because they want to make a difference. We have lost many members over the years due to the feeling that we are not accomplishing anything that improves the lives of our members but are merely pushing paper around. We believe that the statutory intention of this committee is to protect our members and improve the quality of their lives as it pertains to DDD services. To be able to affect real change we need a change in the role that we currently are playing in this committee. We believe that we need more influence in DDD Policy changes and Legislative changes to accomplish the goals of what the statute intended. We started off the year with 12 members and now are down to 6. We lost many members during the pandemic and recruiting was halted. Our committee member numbers are low and need to be replenished.

Training for IOC Committees is an ongoing issue as there is no set curriculum or standard for training new members or refresher training for existing members. We request that there be standardized training for this across the state. We suggest that this could be accomplished with recorded webinars on each topic area that members can watch at their own pace. We were told DDD is working on this. No further information or progress has been discussed with us at this time.

No site visits were conducted, as DDD does not allow the committee access to any residential sites.

### **Meetings**

12 meetings were conducted via Google Meets. Holding virtual meetings increased participation due in part to decreased time requirements and no travel. We invited many different stakeholders to participate; United Health Care, Mercy Care, National Core Indicator liaison, PRC Chair, OIFA leadership, Behavioral support, and District Program Manager. Many of these stakeholders have been regulars in attendance for those meetings.

### **ADOA Administration**

Larry Allen handles the administration for ADOA with all the different IOC Committees across the state. He has been very professional, supportive, and readily available for our committee. The committee wishes to thank him for all his work on behalf of the committee.

## **DDD Staff**

Jeffrey Yamamoto is the liaison for our committee. He is a true professional and has provided excellent support for our committee and never oversteps the boundaries thus allowing us our needed autonomy. Since working with Jeffrey, we have had consistency and follow through. We are incredibly pleased with the Office of Individual and Family Affairs (OIFA) TEAM – Leah Gibbs, Barbara Picone, Richard Kautz and Jeffrey Yamamoto. Richard is retiring soon after 22 years working for the state. He is a very compassionate advocate for our members, and he will be missed.

There has been extreme turnover and unfilled positions for support coordination in District East. There is only a 12% retention rate. After Direct Care workers, Support Coordination is the next most important role for our members and families. They have the resources and knowledge to guide and support our members. In speaking with support coordinators, we found that there is not the up-to-date structured training needed to help them to best perform their job. In addition, support coordinators are not made aware of the resources available to families to provide those families the best support. Low wages, too many cases, and a lack of behavioral health resources all contribute to the low retention rate. In addition, many support coordinators are promoted to other positions due to the high turnover throughout the division. The frequent turnover leaves our members without the continuity of care that is especially important due to their needs. DDD response is “Changed onboarding program engagements and more touchpoints. District more involved in hiring. Executive leadership is more involved with Central HR. Temp to hire added. New toolboxes to be added to managers for staff. Staff engagement team. Listening to more feedback from existing staff. Staff Salaries must fall within budgetary guidelines.” We have not seen any progress yet from these changes.

## **District East Members**

There are currently 9,271 members with long term care benefits, 956 AHCCCS benefits and 992 only case management for a total of 11,219 members being served in District East. Additionally, ATPC has 63 members living in their facilities in Coolidge. There are 45,726 members served throughout the state with 40,662 living in their own homes and 5,064 living in licensed facilities.

## **Program Review Committees**

208 Behavior Treatment plans were reviewed. This year our committee has had a dedicated member, Susan Kingsbury, who has attended all the PRC meetings and made appropriate recommendations to the PRC for necessary changes to the members’ plans. We have found this to be the best way for our input to be heard and implemented by PRC. We are concerned that the PRCs are not meeting the policy mandated number and makeup of members. Many times, BTPs are approved by the PRC Chair and one or two other members. This does not provide the adequate oversight to ensure that these plans are addressing our members' behaviors.

## **Behavior Treatment Plans**

We are now receiving the Behavior Treatment Plans in an electronic format through a shared Google Drive. This has made it so much easier for our committee to review these plans and provide input. The plans are also archived on this drive to allow us to review previous plans as may be required. This reduces lots of administrative and paper waste and increases efficiency all around. We recommend that BTPs be in a consistent format like the members' planning documents. This would allow ease of reading for Support Coordinators, Providers, Direct Care Staff, PRC and IOC. It would ensure that all necessary information is in the plan. It would provide consistency from member to member, agency to agency and district to district. This would prevent agencies from seeking out presenting their plan to the district they feel is easiest to get approval from, as well as help those agencies struggling with creating appropriate plans. It is our understanding that DDD is working to implement a standard template.

## **Incident Reporting Format**

Thanks to the efforts of Jeffrey Yamamoto, as of December 2020 we are now receiving our Incident Reports in electronic format to view in Google Drive. This allows us to be much more efficient. We can ensure that all IRs are reviewed, the comments and old IRs are available in the archive as is necessary for required follow-through. However, we still believe that the redaction of the reports creates unnecessary work for DDD administrative staff and removes important information. For example: redacting the names of staff members involved, doesn't allow us to track and make sure those staff members are not just getting a job with another agency. DDD response is "Redactions are required by statutes."

The committee found that the current IRs do not provide enough information to form an opinion on what occurred. We need to have statistical and expanded information about these agencies, their staff, and clients to get the bigger picture. What was the antecedent? What was the precursor? Is there a guardian? Where do they reside? Is there a BTP in place? Is it working? Number of incidences regarding this client in the last 90 days? Specific information into what exactly happened instead of "member had a behavior". What is the staff: member ratio? What type/s of professional and /or medical help does the members have? How much input or choice does the member have into their situation? DDD response is "– There is a DDD group committee working on the content."

We believe that part of the problem is that staff submitting the IRs are not properly trained on the importance of the IR itself. They choose to summarize the IR down to a few sentences leaving out important details. This information would allow us to make more informed recommendations to improve the quality of life. We also would like more information on specific actions that were taken regarding the IRs to protect our members and prevent further problems. Changing the format of what is required of the providers in making their report would then allow us to have that information. Many pages of the reports that we receive have redundant information.

APS has a very high threshold for “substantiation”. This creates a problem in that there are many times that an individual should not be working with our members, and nothing is done because it wasn’t substantiated. DDD has no investigative abilities on its own and the outcomes are then left to other overburdened agencies.

**Deaths:** Incident reports on deaths many times have very little to no information on the member. We have been told that once the member passes away their date of birth and name are removed from the system. It causes us to not have any ability to figure out what really occurred.

IRs elevated to a “**Quality of Care Concern**” are removed from the system and we don’t receive any answers on what happened. This allows us no ability to do our job of independent oversight as per statutes. We were told by DDD that this is because it goes through peer review, and it is protected by statute. We have not had access to those statutes and further have no answer as to how we are to perform “independent oversight” on files that are unavailable.

### **Direct Support Professional/Direct Care Worker**

It takes very special and very patient individuals to care properly for our members. The quality of life of our individuals is severely impacted by the lack of quality direct care staff, poor training of that staff and **low wages**. It doesn’t matter how well written ISPs and BTPs are if they are not being followed. There is substantial failure on the part of many providers with poor training of direct care staff. Especially since the pandemic started, we have heard many Providers complain that there is a shortage of quality workers.

We believe that DDD policy needs to require a basic minimum that agencies are required to pay to DSP. Currently, according to a 2019 NCI survey answered by our state providers, the average wage paid was \$12 per hour. It is very difficult to find quality DSP with such low wages. Reference: *2019 National Core Indicators® Staff Stability Survey Report*.

### **Federal ARPA Program funding**

Additional funding has become available due to ARPA. It is, however, only temporary funding through March 2022 to be spent by March 2024. It will be a major catastrophe for our legislature to not work with the division to ensure that this funding becomes permanent.

Standardized mandatory behavioral training for direct care staff who care for clients with extensive behavioral needs require ongoing mandatory continuing education to be provided by Behavioral Health Specialists. This would help to minimize use of emergency measures, decrease escalation of behaviors resulting in verbal and physical aggression, property damage, self-abuse, Crisis, and police involvement. Workers having specialized training will be able to better implement behavioral treatment plans and therefore experience fewer behavioral issues from the members. This would create better employee retention and reduce training costs for agencies.

Our members are human beings and deserved to be treated as such. There is an overall theme seen both in BTPs and IRs regarding members wanting to be respected by not being rushed, not being spoken to like a child, not having power struggles with staff, saying no and not giving reasons behind the no, not being sincere, staff not being aware of tone of voice and body language, members not being aware of who is working with them in advance, and members not being aware and informed of their schedule in advance.

### **Article 9 Changes**

Article 9 changes went out for public comment and then came back to the drawing board to address the comments and concerns from the public.

### **Police Involvement**

Many times when agencies call “crisis” they are told to call the police. The police do not have the appropriate training to deal with our members. The police, as well as the jails and courts are not the appropriate place for our members. Involving the police can result in tragedy such as injury or death.

The jails treat them as a typical criminal and do not understand their unique specialized needs. Members have been denied their medications while in jail resulting in further behavioral and medical issues. The experience with the police, jail and the judicial system causes an escalation of behaviors and/or PTSD. Policy changes need to be instituted to prevent these things from happening. These issues are directly in opposition to laws and policies in place to ensure our members' human rights. DDD response is “- BTP should have crisis diversion incorporated into it. Should not be the first line of contact. It’s being worked on by DDD”.

### **Provider Accountability and Provider Report Cards**

There is a lack of quality providers willing to take on highly behavioral members. DDD needs to provide more transparency with members, their families, and guardians. When incident reports are made regarding their member, families deserve to know the outcome of the investigation and any course of action taken by DDD or the agency.

Families should be provided a copy of the contract that an agency has with DDD when caring for their member. This provides clarity of what is being expected for their compensation. There should also be transparency as to the amount of compensation received for services rendered.

Families have the right to know who is working with the member, what their background results are, agency policy for drug tests, and violation consequences/follow up when incidents occur.

Many members and their families are afraid to report agencies and direct care staff for the very real fear of retaliation against the member in their care. Many times if there is any issue with an agency, the family has nowhere else to go for services.



Cameras should be allowed in day programs and residential settings if requested and approved by the guardian. We have seen all too often DCS and APS come back from their investigations with “unsubstantiated” because it is a “he said, she said situation”. Cameras would eliminate these ambiguities and provide protection against false allegations for providers. We find that often our members are not believed and are blamed for circumstances that could very easily be abuse. Our members are thought of as liars or making false allegations. In addition, many times direct care workers are removed from working with vulnerable members for long periods of time while awaiting the results of the investigation.

A report card system needs to be in place so that families can make educated and informed decisions as to the providers that they want to work with. The report card system should utilize feedback from QA, SC and families/guardians and be available on DDD’s website for public access. This has become a common practice for professionals like attorneys, doctors, realtors, general contractors etc. and should be no different for providers. Questions such as: How long have they been in business? Number and category of incidents? Were they corrected? Systems in place? How many homes? Total number of clients? Staff ratio? Staff turnover? How often are clients leaving or providers releasing them? Would be beneficial information.

Agencies experiencing issues should not be given more members to service when they are failing to provide quality of care to the members that they are servicing. There seems to be a lack of accountability of enforcing provider’s contracts to the detriment of our members because the division can not afford to lose agencies because there is a lack of agencies.

### **Health Issues**

Diabetes, obesity, digestive, and other health issues can be a direct result of group homes not providing nutritional meals for our members. Direct care staff eat fast food and drink sodas in front of the members which not only provides a poor example but also results in behaviors due to members wanting the fast food and sodas as well. It is recommended that DSP be trained on proper nutritional requirements to provide nutritionally required healthy meals to members in the homes.

### **CBD and Marijuana**

Due to the conflict between State and Federal laws, our members living in residential settings have their rights violated by not being allowed to buy, store, or consume CBD or THC in their home. We found this to be a problem by not allowing use of CBD for pain and anxiety relief even though it is legal in our state. There is a whole separate discussion as to not allowing recreational use of marijuana for our members even though it is legal in our state.

## **Adequate Residential Settings**

There is a lack of qualified provider agencies able and **willing** to service members with high behavioral needs. This results in members living for long periods of time in unstable and/or potentially harmful situations where they are not happy. This results in decomposition of the member and a worsening of behaviors. Members have the right to be in a happy stable home. Without enough providers willing to take on these members, they are then subjected to neglect, abuse, and a diminished quality of life without the ability to move to another setting. They are subjected to retaliation from providers if they report abuse, neglect, and quality of care issues to DDD, APS or AHCCCS.

There is a need for residential settings that are customized for the members and not just ADH/CDH, Group Homes and IDLA settings. There needs to be freedom to create hybrid models to address these needs. In addition, this year we learned that IDLA settings do not provide reimbursement for transportation to providers. This creates a real hardship for these members. A true person-centered residential plan needs to be implemented. DDD response is "This is being investigated by executive management."

More section 8 housing settings need to be provided for those members who can function outside of a group home but cannot afford to move to another setting due to lack of personal or family funds. DDD's response is "Looking to get more vendors throughout the state for residential services."

## **Transportation**

The transition from Group Home or ADH to IDLA has additional barriers of not providing any kind of transportation reimbursement for providers. The government statutes require that our members are integrated into the community; however, without adequate and cost-effective transportation they are trapped in their home without access to the community. [https://www.ncsl.org/research/transportation/accessible-transportation-state-legislative-update.aspx?utm\\_source=govdelivery&utm\\_medium=email&utm\\_campaign=ODEP\\_Newsletter\\_8-13-21](https://www.ncsl.org/research/transportation/accessible-transportation-state-legislative-update.aspx?utm_source=govdelivery&utm_medium=email&utm_campaign=ODEP_Newsletter_8-13-21). This website provides information on some steps that are being taken by different states to address transportation barriers. We suggest that at a minimum DSP be reimbursed by DDD for providing transportation. However, to give our members the most independence it is also necessary that grants and/or partnerships with ride-share services be provided to allow affordable and accessible integration into our community.

## Employment First

In November 2017, the Governor of Arizona signed an executive order that requires key state agencies to partner with private sector vendors to expand job opportunities to all Arizonans who have a disability through Employment First principles and practices.

Of the 6792 DDD members aged 16 to 64 receiving day services, only 1462 or 21.53% are participating in Supported Employment. There are additional members not attending day service programs that have no employment and nowhere to go, leaving them floundering. With assistance, encouragement, accommodations and support, many more people with disabilities can work successfully in the community. It is imperative to train support coordinators and give them resources to support our members in these efforts.

## Behavioral Health Hospitals

There are no behavioral health hospitals in Arizona prepared to appropriately meet the needs of our members when psychiatric hospitalization is required due to medication changes that need to take place in an inpatient setting. They are thrown in with mentally ill, criminals and drug addicts. This is true in outpatient facilities such as UPC and SMI clinics as well. There needs to be specialization for our members that are set apart as their needs are extremely different due to the developmental issues and would be more effectively managed with specialization. Furthermore, the division between DDD and Regional Behavioral Health causes the dually diagnosed members to navigate an extremely confusing system which has either side pointing fingers at who is supposed to be providing services. Even though behavioral health is now supposed to be under one umbrella for our members there is still a lack of collaboration between DDD and SMI. This collaboration of cooperative care should be a high priority. DDD response is "A Behavioral health hospital is to be established in the valley and is being looked into the integrated Health Plans."

I believe that to make substantial progress to improve the lives of our members there needs to be a shift in the attitude towards our members. They need to be considered valuable human beings and not less than because they don't contribute financially to our society. I believe that if it was another subset of our society that we valued more these issues would be resolved much more quickly. **The most important and impactful change that can have immediate and widespread improvement to their lives is increased pay and training for Direct Care Staff.**

This report is a compilation of District East meetings, statewide meetings, review of Behavior Treatment Plans for DE, review of Incident Reports for DE, meetings with families, providers and DDD employees and personal experiences of our committee members during July 2020 to June 30, 2021.

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Suzanne Hessman, Chairperson