DDD DISTRICT EAST INDEPENDENT OVERSIGHT COMMITTEE

Division of Developmental Disabilities

2020 ANNUAL REPORT

Arizona Department of Economic Security

Independent Oversight Committee DISTRICT EAST July 1, 2019-June 30, 2020 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 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.

Membership

Suzanne Hessman – Chairperson – Parent/Advocate, Realtor
Jennifer Horton – Vice Chairperson – Special Education Teacher
Sheri Reed – Parent/Special Education Teacher, PhD
Sarah McGovern – Parent
Cathy Walen – Guardian, Attorney – Public Defender in Mental Health Court
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 composed 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.

Membership of the committee was 12 members starting in July 2019. Membership of the committee at the end of June 2020 was 9 voting and 1 non-voting member. 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. Jeffrey Yamamoto was trained to be Article 9 trainer, which will be extremely helpful in keeping our committee members Article 9 Certified.

Our committee is made up of volunteers who mostly are employed full time, primarily parents who have children receiving a variety of services from DDD and Behavioral Health. We all bring insight from our experiences with the Division and the agencies providing services. Our diverse insight allows our committee to openly discuss differing points of view to come to a collective decision on matters before us. Dedicating the time necessary to participate on the committee has been a strain at times on our members as they also have had to handle issues experienced by their own children served by the Division; 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 have had a shift in attitude and cooperation with the Division's leadership. Real changes to our administrative processes have made our jobs easier to complete. Jeffrey Yamamoto, our DDD Liaison provides those administrative processes for us, allowing us to concentrate on our mission. However, more change is needed to make a real difference. We appreciate Assistant Director Zane Garcia Ramadan attendance to our quarterly statewide meetings. He has provided great insight into changes in the division affecting our members as well as listening and addressing our concerns during those meetings.

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

COVID-19

March of 2020 brought a lot of chaos with the COVID-19 pandemic. Residential settings, in particular, were unprepared to handle the pandemic. Although they were required to have a Pandemic Plan, many did not and when they did put one together it was merely a piece of paper and not a plan that was followed. They were unprepared in lack of food supply, cleaning supply, and basic essentials. Many plans were not followed to ensure that the virus was not being spread by staff to our members. The plans did not address the issues of isolation, behaviors, needed socialization and family contact.

Meetings

11 meetings were conducted. Starting March 2020 those meetings were no longer held in person, but 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.

Governor's Task Force – Abuse/Neglect Prevention Task Force

Our Chairperson was invited to be a part of the Governor's Abuse/Neglect Prevention Task Force. This group is to address the issues that happened at Hacienda. The Incident Report workflow was created from these meetings.

ADOA Administration

Larry Allen took over handling the administration for ADOA with all of 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 of his work on behalf of the committee. ADOA produced a manual for all of the IOC committees, which was approved. ADOA created a website for the IOCs and agendas and meeting minutes are posted there. ADOA also started a newsletter to go out to all IOC Committee members. New badges were issued with ADOA instead of DDD information on them.

DDD Staff

Three HRC Liaisons were hired for the entire state however, due to circumstances we only have had Jeffrey Yamamoto as the liaison for the entire state. 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.

There has been extreme turnover and unfilled positions for support coordination in District East. There is only a 12% retention rate. 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, 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.

Program Review Committees

280 Behavior Treatment plans were reviewed. PRCs are not meeting the 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. Many of these plans approved are being written by an outside agency with little to no information on the member they are writing these plans for. We find plans that are cut and pasted and sometimes do not even have the right member's name on the plan. Behavior Treatment Plans are important in protecting our member's rights, otherwise we are essentially just medicating them and not teaching a replacement behavior. We have also become aware that legal guardians are not being notified of when the PRC will be reviewing their member's BTP. Plans are being created without input from legal guardians and other team members.

We have had an ongoing issue with the DE PRC not working with our committee. In essence our dispositions are completely ignored. With the makeup of our committee comprising mostly of members who are employed full time, we are unable to attend the 1-2 days per week PRC meetings to provide our recommendations. We have implored the PRC chair to provide those BTPs to us so that we can make our recommendations prior to the meeting, however these requests have not been addressed.

Incident Reporting Format

10, 398 Incident Reports were reviewed. It takes so long for reports to be investigated that by the time we review them the point is moot. 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.

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". The word "behavior" should not even be allowed. 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?

We are receiving poorly written IR's because staff submitting them 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 it is clear that an individual should not be working with our members and nothing is done because it wasn't substantiated.

Direct Care Staff

Our committee found that 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. We read wonderfully written ISPs and BTPs only to find that they are not being read by agency providers and therefore not being followed. There is substantial failure on the part of many providers to professionally train direct care staff. Providers complain that there is a shortage of quality workers.

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.

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.

Behavior Treatment Plans

Behavior Treatment Plans should be in a consistent format like Individual Service Plans created by Support Coordinators. This would allow ease of reading for Support Coordinators, Providers, Direct Care Staff, PRC and HRC. 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.

Our committee requests that it be provided with a behavioral consultant to provide expertise into the effectiveness of the plans that are presented.

Currently when an AIMS report shows that a member is having negative side effects from the behavior modifying medication there is no follow up or action taken by the Division to protect the rights of the members.

Article 9 Changes

We have been told that changes are being made to Article 9. We have not been informed or consulted on what those changes will be and how it will affect our members.

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 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.

Provider Accountability and Provider Report Cards

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 members, 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.

Cameras should be allowed in day programs and residential settings if requested by a 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 more often than not, our members are not believed and are blamed for circumstances that could very easily be abuse. 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 the provider is 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.

Health Issues

Diabetes, obesity, digestive and other health issues are oftentimes 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. This year we have addressed issues where group homes are refusing to provide nutritionally required healthy meals to members in the homes.

We read a few incident reports regarding a group home or DTA van arriving at their destination, only to later discover a member was left in the van by themselves. Incidents such as this can lead to neglect, medical issues or death. It is extremely important that group homes and DTAs have systems in place to ensure that this never happens.

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.

More section 8 housing settings need to be provided for those members who are able to function outside of a group home, but cannot afford to move to another setting due to lack of personal or family funds.

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. Behavioral health needs to be under one umbrella for our members. This collaboration of cooperative care should be a high priority.

These issues and recommendations have been previously discussed with DDD management via phone, email, District East meetings, statewide meetings, and individual meetings.
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 2019 to June 30, 2020.

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Suzanne Hessman, Chairperson