Independent Oversight Committee DISTRICT EAST 2018 + 1st Half 2019 ANNUAL REPORT

Division of Developmental Disabilities

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

Independent Oversight Committee Function

Human Rights 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.

Our primary efforts have been focused on reviewing Incident Reports given to us by DDD Quality Assurance 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. In addition, we have advocated and counseled with individuals and their families.

We look at data trends regarding provider's and the number of incidents they report in a given time period, 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.

Membership

Suzanne Hessman – Chairperson – Parent/Advocate, Realtor
Jennifer Horton – Vice Chairperson – Special Education Teacher
Sheri Reed – Parent/Special Education Teacher, PhD
Tammy Leeper – Parent/Nutritionist
Mindee Stevenson – Parent
Sarah McGovern – Parent
Cathy Walen – Guardian, Attorney – Public Defender in Mental Health Court
Susan Kingsbury – Counselor
Elizabeth Bird – Parent
Cynthia Elliott – Parent
Lindy Fisker – Parent

Kin Counts – parent
Cherrie Floyd – RN mental health setting
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.

Training is an ongoing issue as there is no set curriculum or standard for training new members. This needs to be standardized across the state. This could be accomplished with recorded webinars on each topic area that new members can watch at their own pace.

Our committee is made up of individuals who 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 children served by the Division; however, they chose to serve in order to make a difference.

During calendar year 2018 12 meetings were conducted. During January-June 30 2019 there were 6 meetings conducted.

For 2018, 3295 Incident Reports were reviewed. 305 Behavior Treatment plans were reviewed. 865 volunteer hours were reported. Membership of the committee was 10 members in January 2018. For 2019 first 6 months, 4544 incident reports were reviewed. 57 Behavior treatment plans were reviewed. 498 volunteer hours were reported. Membership of the committee at the end of June 2019 was 11 voting and 1 non-voting members.

April 2018-August 2018 Quality Assurance started to increase their reporting practice and the number of Incident Reports increased in District East from under 100 a month to 200-400 per month.

August 2018 Senate Bill 1450 was instituted and the newly named Independent Oversight Committees will now receive incident reports in all 12 categories. August 21st, AD Maureen Casey stated that DDD will report all incidents given to DDD, no longer using criteria for reportable incidents. This increased IRs to 800-1000 per month in 2019.

Behavior treatment plans were low in 2019. There was no PRC Chairperson from April-June 2019 and therefore all of District East plans went to District West for review.

No site visits were conducted, as DDD doesn't allow the committee access to any site visits.

November 2018 our committee was trained by Tim Payne on Article 9. Jeffrey Yamamoto was trained to be Article 9 trainer, which will be very helpful in keeping our new committee members trained.

ADOA Manual & Website

ADOA produced a manual for all of the IOC committees. We submitted our comments and are awaiting a final copy. ADOA created a website for the IOCs and agendas and meeting minutes are posted there.

Quality Assurance

There has been a lot of confusion with the Quality Assurance Department. We were told they were dissolved, and their duties were being taken over by a private 3rd party. Then they came back and now we are hearing hints that they are looking for a 3rd party again.

DDD Staff

2018-2019 was another year with lots of changes for the division. DDD has gone through so many Assistant Directors in the last few years that we can't even keep them straight. District East has had multiple District Program Managers as well. The PRC Chairperson in 2018 – April 2019 refused to forward on our BTP recommendations to agency providers, which rendered our advocacy for our members as moot. Three HRC Liaisons were hired for the entire state. Jeffrey Yamamoto is the liaison for District East. He is a true professional and has provided excellent support for our committee and never oversteps the boundaries thus allowing us our autonomy. Since working with Jeffrey, we have had consistency and follow through. We are very pleased with the HERO unit – Barbara Picone, Richard Kautz and Jeffrey Yamamoto.

There has been extreme turnover and unfilled positions for support coordination in District East. There is 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 in order to provide those families the best support. Low wages, too many cases, lack of behavioral health resources all contribute to the turnover. The frequent turnover leaves our members without the continuity of care that is especially important due to their needs.

Program Review Committees

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 don't 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 with out input from legal guardians and other team members.

Incident Reporting Format

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, 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? 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.

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 properly train direct care staff. Providers complain that there is a shortage of quality workers.

The passing of the minimum wage law caused many issues for providers. Many smaller providers were not able to keep their businesses open. In some cases, larger agencies picked up the slack and in many more, members were left with no services.

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 less 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 be 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 don't 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

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.

Cameras should be allowed in day programs and residential settings if requested by 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 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

In October 2016 $1000 allowance was implemented for dental care for our members over the age of 21. Many members are having teeth pulled resulting in additional health problems, such as digestive issues and gum cancer. Providers are not providing adequate daily dental hygiene to the members.

Diabetes, obesity, digestive and other health issues are often times 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.

Human Rights

Providers are refusing to take and support members in their religious activities because it differs from their own religious beliefs. It is important that agencies train and enforce direct care workers to understand that their job is to support the member in the activities they wish to participate in.

Agencies are not respecting cultural sensitivity of our members. Members are forced to have direct care staff that are very different from the members causing the members to be uncomfortable and not get their needs met. These cultural differences were seen in having thick accents which caused problems in communication, religious preferences not being respected, meal preparation of an origin not comfortable to member, staff not knowing how to brush hair different from theirs and staff not comfortable with member's pets due to cultural differences. Our members have the right to have staff that they are most comfortable with.

Adequate Residential Settings

There is a lack of 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.

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 very 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 2018 and January to June 30, 2019.

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Suzanne Hessman, Chairperson