

July 20, 2022 - 10:00 am to 12:00 pm

This meeting took place by electronic means due to concerns about Covid-19. There was not a physical location.

Call to Order

Meeting was called to order by Linda Mecham. The date was July 20, 2022, at 10:05 am. The address of the meeting was Virtual, no physical address.

Welcome and Introductions

Present:

- Suzanne Hessman (District East Committee Chairperson)
- Keith Jansen (District South Committee Vice-chair)(Facilitator)
- De Freedman (District West Chairperson)
- **Bob Malloy** (District North Committee Chairperson)
- Linda Mecham (District Central Committee Chairperson)
- Sherry Wilhelmi (District Central Committee Vice-Chairperson)
- Kin Counts (District East Committee member)
- Bernadine Henderson (District West Committee Vice-Chairperson)
- Eva Hamant (District Central Committee member)
- Jeffery Yamamoto (DDD IOC Liaison)
- Zane Garcia-Ramadan (Assistant Director of DDD)
- Dr. Tony Dekker (DDD Chief Medical Officer)
- Leah Gibbs (OIFA Administrator)
- Joan McQuade (DDD OIFA/Chief advocate)
- Larry Allen (ADOA liaison)
- Michelle Rademacher (IOC Liaison)

Health Plan Present:

- Karen Kramer (United HealthCare)
- Vera Kramerchuk (Mercy Care)



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Public Attendance:

• None

Call to the Public

Linda Mecham: Made a call to the public: There was not public present

Ammonia Toxicity and Depakote Presentation by Dr. Decker

Linda Mecham reported that four of the District Central IOC committee members have been affected with members who have experienced ammonia toxicity. Three of the four were not receiving regular blood work for the ammonia toxicity. This comes as a result of Depakote medication administration. The fourth member said that her primary care doctor recommends quarterly bloodwork to monitor. One of our members' son was hospitalized for over a week. Her son is back in the hospital. They have taken him off the Depakote and cannot stabilize him.

Dr. Tony Dekker introduced himself as retired from federal service after thirty-seven years. He spent most of his career on the South side of Chicago as a family physician and an adolescent medicine developmental specialist. He transferred to Kansas City as an academic and also Chief of region seven for Job Corp. In 1998 he moved to the Phoenix Indian Health services as chief medical officer for all ambulatory services until 2010. He then went to the US Army as a civilian where he ran the substance abuse disorder and pain medicine programs. In 2015 he came back to Arizona, stationed at the Prescott VA. In 2020 he transferred



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out of the VA to help Gallup Indian medical services. He stayed there until the end of 2021 until joining DDD. He has a 51 year old sister who has Downs Syndrome.

Dr. Dekker reports the situation is worse than you think. Valproic acid which is the generic name for Depakene which later developed to Depakote due to putting a coating around the pill. It is an anti seizure medication. It is a mood stabilizer for individuals who have a significant emotional reving up. It seems to minimize that process. Dr. Dekker reports he is an Osteopathic physician. The use of valproic acid has been challenged with some individuals developing difficulties in metabolizing the medication through their liver. The protocol has always been to get quarterly if not monthly levels of valproic acid to have an assessment of therapeutic level of valproic acid. You also want to assess for prevention of liver problems. Liver enzymes and ammonia builds-up when people are having liver difficulties. There are five precepts to osteopathic medicine: 1. Body has the ability to heal itself, we facilitate that process; 2. Surgery should be avoided until no other option exists; 3. All medicines are poisonous and should be used in the smallest effective dose; 4. Every disease affects the entire person; so it's a Holistic approach 5. Since every disease process affects the total body, we also treat the body. Allopathic medicine, Mds, diagnos, prevent and treat diseases. DOs diagnose and treat function. The two professions have begun to overlap and now are very close together. We want to give enough medication so the individual responds to it, we don't want to give too much that makes the member ill. The Institute of Medicine has identified that at least 100,000 people in the US die every year from medication errors and medical errors. We have 1700 members in DDD who are on valproic acid. We did a look back from the past year, 58 % have not had any labs done, of the 42% who had labs done, only 1% have had ammonia levels checked. Dr Dekker is working with the Directors of United HealthCare and Mery Care to reeducate their providers and to at least monitor their providers so the valproic acid is used in the smallest effective dose necessary. We identify individuals who have rising ammonia levels or changes in their liver enzymes so we can make adjustments. We want to maximize efficiency and minimize side effects. As a Medical Director, Dr. Dekker states he is highly invested in making sure that our members receive the best of care. That means if there are medications that help improve their function so they can interact with others in an appropriate way, decrease the likelihood of hurting themself or others, he is all in. We want to make sure they don't have side effects that are predictable.



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De Freedman stated that she dealt with the medication and issues related with her family member 15 years ago. She stated there needs to be more doctor education. She also reported concerns when doing program review of behavior plans. There are behavior plans where the medication lists do not match up within the same behavior plan. She stated Dr. Arnold reported that the providers are responsible for the behavior plan. De finds it very disturbing that the behavior plan, which is a medical record, that the plans are not accurate and we are not paying attention to the medication interactions, we are not holding the prescribing doctors accountable that those things are being looked at. There are questions related to Article 9, whether or not effects of medications are being looked at. De stated provider assurances should be in place that blood tests are being done when they are supposed to be done and the health of these individuals are as good as they can be given the circumstances.

Dr. Dekker stated the behavior plan is provided by the vendors and they are not medical providers. We are asking the vendors to work with their contracted health providers to update the behavioral treatment plan. Providers are responsible for medication reconciliation. Attending physicians need to review all the medications. We need to have checks and balances that improve safety and decrease complications.

Linda Mecham shared the story of her son's experience with Depakote and ammonia toxicity. We were hoping that this medication could be elevated in the AHCCCS list. Linda quoted Karen Kramer (UHC): the AHCCCS drug list specifies what medications require a prior authorization prior to dispensing. Depakote does not require a prior auth. The responsibility for monitoring Depakote lies with the prescriber. If a prior auth. is required by AHCCCS, it would mean that the blood work is automatically required and helps to alleviate some of these issues. Do you think that it is possible to elevate this medication?

Dr. Dekker feels a prior auth. is not the solution because we already have 1700 members already on the medication. He worries if we change the list, we might have issues with things getting blocked. We don't want the medication stopped abruptly. Depakote is not the only medication that needs monitoring, Levothyroxine and Tegretol. There is no required curriculum in the Arizona state



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medical schools (until this year, only in Tucson) which requires DDD education, of understanding the genetics of DDD and the cure of adults with DDD. Tucson is implementing three hours a year of education to their curriculum. We are trying to get every teaching medical institution in Arizona to enact the training. Dr. Dekker states he will work with the health plans and with AHCCCS so that every primary physician is monitoring the effects and side effects of the medications prescribed to our DDD members. We work with the doctors who care for the members. The intent is to work within the system to raise the level of function so we no longer have this problem.

Keith Jansen added the comment that behavior plans will receive exemptions on submitting plans. This could create an issue with the information not being dispersed.

Dr. Dekker states that behavioral plans are not the only thing that determines medications. DDD has a full time pharmacist. He does believe we can make a positive change. We have people who are committed to making sure these mistakes are not going to be repeated mistakes.

De Freedman asked if the medical schools have the option as an elective to choose DDD training.

Dr. Dekker reported 4 out of 150 students took the elective course. He believes elective options are not good enough and every doctor needs the education.

Sherry Wilhelmi commented that we need to raise the awareness of the 1700 persons on Depakote. How about a newsletter to announce you need to have labs for ammonia toxicity? Parents can take that information to their physician and ask for the lab testing. There is a lot of power in empowering the parents to say something.

Dr. Dekker we need to look at all these things we are using to help members have a healthy life and long life. We need to be as positive as possible and minimize the side effects. He states he will talk it over with the DDD pharmacist to see if we can institute something like a newsletter notifying members of potential side effects to their medications.



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Dr. Dekker stated that if you are not treated well by your doctors, let us know. We will work with the health plan for a new doctor. He believes most doctors are conscientious and want to do the best for our members.

<u>District Updates</u>

Linda Mecham reports we discussed Depakote and ammonia levels, and worked with District West on compiling comments for Article 9. District Central has three new members and is voting on a fourth at our next meeting. District Central is working on the annual report.

De Freedman communicated the committee is on a summer recess. The next meeting is the fourth Tuesday in August. We along with District Central did an amazing amount of work in May regarding Article 9 and the proposed changes. It was available through the IOC website at one point. Last time I checked a couple of weeks ago, those minutes were not available due to web issues. Expectations are it will be back up on the website.

Suzie Hessman communicated they are doing well. District East had no hiatus on meetings. We have been increasing our membership with three new members. We are keeping up on IRs and two members are dedicated to attending PRCs.

Robert Malloy reports District North has three members and hisself. Membership is stable. Keeping fingers crossed.

Keith Jansen shared that Chere, the district chair, had to leave because of a family crisis. Next month we should be voting for a new vice chair. District South is keeping up with the IRs and more people are involved in doing the IRs.

Linda Mecham informed the IOC committee members cannot be paid by DDD as part of the Independent Oversight volunteer program.



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<u>UHC Healthy Food Card Program Overview</u>

Sherry Wilhelmi reports the healthy food cards were brought up due to her daughter's card being canceled without notice. It took quite a bit of time to get it renewed. She stated Eva is curious about how many members sitting in group homes are not receiving the benefits. The whole process changed without any notification. Sherry is concerned that a lot of people are missing that benefit.

Eva Hamant reported we got our card. The problem is finding the right store to use it at and the cashier knowing how to process it.

Karen Kramer reports she is not an expert on the Health Foods program. She will include her email with the overview of the program, <u>karen_kramer@uhc.com</u>. If you have questions, please reach out and she will request information. Dually eligible members, Medicare and Medicaid receive the benefit. You get \$125 for groceries and/or over the counter products. Credits expire during the last day of the month. Shopping can be done online, at the store, by catalog, by mail and by phone. An app is available which enables the item to be scanned to know if it is eligible. Members can shop at Walmart.com and products are delivered to their home. Members can purchase healthy meals through Mom's Meal, pantry boxes, produce boxes and reduced cost meal plans. Stores in Arizona include: Albertsons, CVS, Fry's Food, Fry's Marketplace, Walmart, Safeway, and Walgreens. Catalog comes with an order form with member information already pre populated and an envelope with prepaid postage to send in orders. Once the card is received, a phone call will activate it. New this year, registering a HealthySafe ID online, allows the member to purchase products through myuhc.com/communityplan/OTC.

Vera Kramerckuk reports there is not anything comparable to this program with Mercy Care.

Karen Kramer shared the card will be sent out to the address United HealthCare has on record. She will inquire if a duplicate card request can be made and sent to the group home. She also wanted to share that receiving food stamps does not disqualify a member from receiving the service.



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Updates on Concerns Related to Abuse & Neglect Member Curriculum

Zane Garcia-Ramadan earlier this week, we sent out a survey on the abuse and neglect training curriculum. It will be open until mid August to collect feedback. Once feedback is collected it will be combined with the feedback from the IOCs. A workgroup will convene to look at the feedback and determine what adjustments need to be made to that curriculum and work toward making those changes. We welcome participation from the IOC as part of that workgroup which gets together and views the feedback from the survey.

Linda Mecham formally apologized for the tone that she took with Zane in the past meetings. She is passionate about this topic. She got a copy of the newsletter. She got a copy from two providers. A couple of IOC committee members stated they did not receive the newsletter either.

Leah Gibbs explained the e-newsletters go out once a month electronically the information is within the content of the e-newsletter. She will make sure the IOCs get a copy.

Linda Mecham stated the District Central IOC made a motion in the past and Linda believes the committee has not heard the final outcome. Linda read the motion as follows, District Central IOC is seeking to gain additional information which is not available through the investigation process (DDD QA investigative process). In reference to incidents that relate to sexual abuse, the committee is asking that some additional information be requested through questions given to the support coordination teams duing incident follow-up. The committee would like additional questions added to the scopes which are included in the incident notes sections of incidents for follow-up by Support Coordinators

- 1. Did the member who was involved in the incident of Abuse, Neglect or Exploitation participate in the required Abuse and Neglect training? If yes, ask when did the member last take the training?
- 2. Was the member able to complete the entire course? If not, why not?



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3. Has the team identified any changes in behavioral patterns since the member took the training? If yes, what are they? Was it a direct result of the Abuse and Neglect training? Were there previously no concerns about this and now there are? Did this raise the awareness in the mind of the member? Linda expressed the committee thought that might help DDD with regards to some of the effects the Abuse and Neglect training might have as well as help with getting to the root of the actual incident.

Zane asked a clarifying question. He asked about putting the questions on the incident report template or part of the follow-up investigation. Linda clarified that Eva asked questions per review of IRs during a committee meeting and James Maio, DDD DC QA stated that is not a question as part of the investigation, but could perhaps be added to the scope of the investigation. Zane stated he would take that motion once received to the Quality Management team for a conversation.

Leah added the motion was sent in May. The Division did provide a response and let them know that those recommendations were added to the list of things through the incident reporting process that we are working on as we are rolling out changes and we do still have it.

Sherry Wilhelmi stated a mother expressed to her that her two children are still masturbating in public since the training. That is part of why we are asking for this. The behavior was not present before, got the training, and now she can't take the kids out of the house because of the issue. She is not a happy parent. Her kids were not aware prior to the training. Zane recommended passing the survey on to this parent for her feedback and input. She has a behavior coach in place to assist. Sherry states she is aware of two past trainings that were done in the past that were not so graphic. The teaching concept was simplistic and easy to follow.

Update on Archived records - Obtaining Old Member Records

Sherry Wilhelmi stated she was looking for documents per her daughter's job training. Sherry was looking for records and found they only go back to 2015. Sherry wanted to find Carolyn Chapelin's notes to include that her daughter did the Voc. Rehab process so she could send the documentation to



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Steve Marcello for employment services for her daughter. Sherry states she got two boxes with CDs to review. She stated the Division was going to call her and report to her what they have. Sherry states it would have taken one email to get her the information she wants. She want's job services for her high functioning child. Sherry also wants to know how many parents are going to have to sort through an entire lifetime of records to find the documentation they need?

Joan McQuade added information to explain the records request process. She stated that the request can be specific so not all records are sent to the responsible person. Joan stated that specific dates on the records requests can be input in your request and specific information to explain what the topic of the documentation is. The link for requesting records is on the DDD website

https://des.az.gov/services/disabilities/developmental-disabilities/current-member-resources/records-r equests . Accessing member records which have been archived (not available from Support Coordinator through OnBase) is achieved by sending a formal request for records to DDD. This can be done though the DDD public website at

https://des.az.gov/services/disabilities/developmental-disabilities . Members may write, fax, or email a request for their records: Division of Developmental Disabilities, Attn: Records Management Unit, 1002 S 63rd Ave Unit 102/2HE6, Phoenix, AZ 85043 or Fax: (602) 807-5001or Email: DDDRecordsrequest@azdes.gov .

De Freedman asked what do we do when the member is their own guardian and may not be capable of navigating through the website and making such requests on their own behalf? Linda also asked, isn't that support incumbent upon the team to assist the member get what they need?

Zane Garcia-Ramadan clarified in the scenario when the member is their own guardian and needs support in the act of physically submitting a request themselves, the Support Coordinator should be providing that support. In the scenario where the member has a guardian or responsible person, I believe it is appropriate for the Support Coordinator to have that individual make the request to the Division for the records.



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Update on Article 9

Zane Garcia-Ramadan stated we have reviewed the comments that were received. The District West along with the Autism Society comments did represent about 50% of the comments received. We are making some final adjustments, about 10 minor changes to Article 9 regarding language and other minor revisions. Regarding the letter, Zane stated he would be happy to meet and go over the letter and clear up the confusion or misconception. Zane stated there is a lot that is not true. For example things like, we have eliminated the requirement that DDD employees and qualified vendors must complete Article 9 training. That is not true. That is still a requirement. We've eliminated the requirement that within one working day a report must be submitted. That is not true. The language changed from one working day to 24 hours. Zane stated he wished we had the opportunity to go through this with all of the IOC members. We did have some from the IOC present at the meeting to explain the changes. Zane reviewed the development of the changes which started in 2021. We had the public comments, we received the opportunity to make some changes and do it in an inclusive manner to include members from the IOCs, from the Division, qualified vendors, behavioral health providers, from the National Association of State Directors of Developmental Disabilities. Through all of these representatives, IOCs were the most represented in that workgroup and we came to what we all thought was an agreed upon product to move forward. We put that forward and it seems the most concerns that came in were very similar to what the concerns were before. Article 9 has not been updated since 1994. We have a requirement to update rules every five years. There is nothing in the changes that are allowing things to occur that we did not allow before. Zane said there was something in the comments that said we changed the verbiage from prohibited to shall not. The standards for Arizona rulemaking require that language of "shall not" equals "prohibition". Zane feels that we have been as transparent as we can possibly be, inclusive, etc.

De Freedman said the opportunity to talk through the so-called inadequacies was not given timely. We had 30 days to respond. We did the best we could with the 30 days we had to respond. We requested more than 30 days at a statewide meeting knowing that the law was going to change for the



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future. We were not given extra time despite a public meeting request. The opportunity to meet with DDD staff was after the DW IOC had met to do our own compilation of the letter. It was a joint committee venture between District West and District Central. We acted with the resources that we were given. DDD could have offered to meet with us beforehand. We met with our own experts. We went through the materials. That is what we felt. If what is presented to GRRC is the same thing, we will bring our concerns to GRRC. It will be up to GRRC to determine what it does.

Zane asked for an opportunity to meet with District West before going to GRRC, Governor's Regulatory Review Committee. Zane said he hopes that we can improve communication and you with District West do not feel you cannot engage in a conversation with DDD leadership about this topic and you do not have to go to other avenues instead of having that conversation with us.

De Freedman stated if Zane is offering the opportunity to now meet with DDD staff she would ask the IOC. The District West IOC meets the fourth Tuesday of every month. She stated you are free to provide us with expertise.

Linda Mecham stated Zane communicated he was going to send a copy to the IOCs as soon as it came out. She stated it came out on Friday. The following Monday, a copy of the behavioral support manual was received from Jeffrey. That is not Article 9 it is the policy. Linda stated she got a copy from the Secretary of State's website and distributed it to the IOC. Linda stated that she reached out to Mary DeCarlo and was told to submit through the public comment process. Linda reported she felt that the IOC was on their own. If we are submitting something as an IOC we have to have the approval of the whole committee to send it in as a representative. We had no time after the DDD meetings for Thursday and Friday since the commenting period closed on Monday. That is why we requested with Senator Barto's help that we receive comments like this or articles or policy changes 30 days before it goes out for public comment so we have time to study it, we have time to meet, and we have time as an IOC to vote how we want to move forward and what our comments would be. That is our responsibility.



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Sherry Wilhelmi stated that the very first draft came out to the IOC less than 24 hours before we had to it was due for comment. We have been asking for Article 9 for two years. We have asked for drafts. We asked for inclusion.

Zane Garcia-Ramadan reported there were four IOC members who participated in the Article 9 rewrite committee. To hear that you were not included in the process, he does not know what to do. Zane asked for an opportunity to meet with District West IOC in August which would be prior to the changes proposed going in front of the Governor's Review Committee. As a timeline we are hoping to file the final package GRRC by September 2022. GRRC would have 120 days to consider the package. If it moves forward it would be posted with the Secretary of State's Office then it would be effective 60 days from when it is filed with the Secretary of State's Office. The new Article 9's effective date would be in early 2023. We are hoping to have the behavioral support manual ready to post the new behavioral support manual along with the new Article 9.

Sherry Wilhelmi stated we are back to chemical restraints. We are losing positive behavioral support, PBS, that was required. We stopped training our staff in PBS, it used to be a requirement.

Zane shared that part of the ARPA funding plans includes positive support training that all direct care workers would be required to take and any family members that are interested. That notion of positive behavior support training is something we want to ensure our system is educated on. Over the course of the next two years we will be getting that out to all 50,000 or so direct care workers. **Leah Gibbs** shared that we will be developing a committee that will be assisting us with this.

DDD Updates: Assistant Director Zane Garcia-Ramadan

Zane Garcia-Ramadan provided an update on the staffing challenges throughout DDD primarily in Support Coordination. The impact is being felt. He reported that we are starting to make progress. From March 2021 through the end of February 2022 DDD experienced a net loss of 75 support coordinators. That contributed to high caseloads and overwhelm. Between March 1, 2022 through June 30, 2022 net gain of 24 support coordinators. In the most recent budget passed through the state



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of Arizona, a pay increase across the board with a little more for Support Coordinators. Zane feels we are going to maintain the upside of the staffing especially with the ability to pay Support Coordinators more. On top of that the Support coordinators have successfully been able to implement the person centered service plan, new support plan, 98% are up to date (2% are loss of contact members).

Zane reported on legislative updates, a number of bills, around twenty, that impacted DDD. The majority are slight policy changes that will need to be implemented and anticipated not a big impact. There are five or six that passed that will be highly impactful: House Bill 2113 adds Down's Syndrome as the fifth qualifying diagnosis for DDD eligibility (individuals will need to have 3 of the 7 functional limitations to qualify); HB 2865 requires a designated entity to monitor and inspect in person all group home for clients with complex needs and further requires DDD to establish a referral system to ensure that quality of care complaints are transferred to that entity for investigation. We expect it may be the Centers for Disability law. Another element to that which will impact the IOCs is beginning January 1st, 2024 DDD is required to provide an annual report to the legislature that includes a lot of statistics from incident reports as follows: number of incident reports received from group homes, categorized by level of severity, categorized by those that resulted in contract sanction, those that involved medication errors, those that involved changes to behavioral treatment plan, those that required additional staff training, those that involved law enforcement and about 10 more categories. We as a division are recognizing tracking needs to change. DDD may want to build on the new incident report template that IOCs helped to develop and add some of these new fields to that template. Zane is anticipating DDD may reconvene the and be revisiting the incident reporting template workgroup. SB 1542 update to the legislation on electronic monitoring in group homes. In the bill, if all the members and their responsible persons consent to video monitoring in the common areas of the home, it would prohibit the provider from preventing installation of cameras. Installation and cost of electronic monitoring would be assumed by the family- responsible person. The providers would not have access to that data without consent. SB 1230 includes additional funding for provider rate increases. DDD will be holding five forums in August, two exclusively for members and families, two for providers, and one joint meeting so DDD can receive feedback and adjust the proposed rate increases. SB 1231 states that DDD must provide



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up to 30 for IOCs to review policies and major changes to policies before posting for public comment. We have already implemented this.

Zane talked about additional initiatives DDD is going to pursue through ARPA. The majority of the State of Arizona's ARPA spending plan is toward adjusting the Direct Care Worker, DCW, compensation challenges we have. To address that, in May 564 QVAs received an initial payment. Requirement which was attached to the payment is that at least 80% of the funding would go to direct care worker's compensation. We are on a good path toward getting our DCW better pay. We are requiring vendors to provide quarterly reports per turnover rates, how many staff pre-payments/post payments. In addition to that we are attempting to pursue through ARPA (once AHCCCS approves): positive behavior support training to all DCWs, plus family members. We are also working on a system for Behavioral health training for providers of DDD members to increase the Behavioral Health network in effectively supporting our members. DDD is working towards updating our case management system to be more modernized with the time. Support coordination system in use currently is nearly 20 years behind.

Eva Hamant asked about the second ARPA payment date. Zane stated DDD anticipates that it will be early August.

Linda Mecham states her committee came up with an issue per the person centered document related to the Health and Safeguards section being no longer included. PRC recommendation was to include the documentation in the medical portion of the person centered planning document. Linda stated it was not appropriate in that section. Zane recommended the committee send requests through the formal process so DDD can send to AHCCCS for approval for a modification to the document.

Updates From DDD Staff

Leah Gibbs stated we are working on a Positive Behavioral supports training and she is passionate about the program. She invited Sherry to participate in the planning process. Eva added that if you talk about positive behavioral supports you need to talk about person centered training.



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Michelle Rademacher (IOC Liaison) reported that the determination on which liaison will be assigned to which district has been made. **Jeffrey Yamamoto** will be the primary liaison for District East, Central, and Statewide. Michelle Rademacher will be the primary liaison for District North, South and West.

There were no other updates from DDD Staff.

Roundtable Topics for Next Meeting

No one had any topics.

Next Meeting Date/Time/Facilitator Discussion

Jeffrey Yamamoto The next meeting will take place virtually on October 19, 2022, at 10:00 am. The Facilitator will be **De Freedman**.

Adjournment

The meeting was adjourned at 12:38 pm by Linda Mecham. The next meeting will take place virtually on October 19, 2022, at 10:00 am. The Facilitator will be De Freedman.