



**Division of Developmental Disabilities
District Central Independent Oversight Committee
Meeting Minutes
Monday, February 24, 2020 – 10:00 AM**

Call to Order

The meeting called to order by Committee Chairperson, **Karen Van Epps** on February 24, 2020 at 10:15am. The meeting was located at 4400 N Central Ave, Ste 900, Phoenix, AZ 85012.

Welcome and Introductions

Attendance in Person:

- **Andrea Potosky**
- **Karen Van Epps**
- **Eva Hamant**
- **Debbie Stapley**
- **Carol McNulty**
- **Eduarda Yates**

Attendance by Phone:

- **Sheri Wilhelmi**

Members Absent:

- **Linda Mecham**
- **Heidi Reid-Champigny**
- **Mandy Harmon**
- **Lisa Witt**

Public in Attendance:

- **Vera Kramarchuk** (Mercy Care)
- **Sophie Legaspi** (United Healthcare)

ADOA:

- *No ADOA staff present at the meeting*

Division of Developmental Disabilities:

- **Eric Houghtalin** (IOC Liaison)
 - **Diane Murphy** (Revenue Desk)
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ADOA and DDD Updates

DDD - Eric Houghtalin: advised that we are working on recruitment again and asked for IOC members to send leads directly to him.

ADOA - *No ADOA staff were present at the meeting.*

Supported Decision-Making Discussion

Carol McNulty: advised that she read part of the proposed bill and hadn't finished it yet. She noted her concern about the legal responsibilities of the members with their own guardianship under this measure.

Karen Van Epps: advised that the bill was brought forward from the ARC and autistic parents. She advised that the ARC had a fact sheet and there was a presentation by **John Meyer** about why it was necessary. She stated that she believed that they (ARC and autistic parents) didn't want guardianship for people (DDD members).

Eva Hamant: advised that there should be no issue with the bill. She noted that they (the State of Arizona lawmakers) took from other states that have already adopted. She advised that according to the current statutes that support decision making was not possible.

Karen Van Epps: added that supported decision making has no legal basis. She noted that she has spoken to **Rob Beckett** (author of a paper for a national organization) and he told her that there was no need for it. She advised that there could be supported decision making without a law.

Carol McNulty: asked what happens when dealing with a vendor.

Eva Hamant: added that it isn't for everybody. She noted that it's for individuals that don't want to deal with going to court. She advised that in the school districts (right before a member turns 18), that the family is told that they need to get guardianship or otherwise they won't talk to them.

Karen Van Epps: advised that the schools were saying that they (the parents) couldn't sign for them (after turning 18 without guardianship in place).

Eva Hamant: added that it has been an issue in the past that if the family were not the legal guardians, they didn't have to communicate with the family. She noted that this can be used as a means of manipulation over the family and the IEP as well. She noted that in order to get guardianship, they (the family) would have to go to court. She added that supported decision making would make it possible to provide supports for people that don't want to go to court. She noted that all states that currently have supported decision making have found that they need to put it in statute so that the legal protections can continue. She asserted that supported decision making would help to keep members from losing their rights. She added it (supported decision making) is for people who



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have support in the community. She advised that members with power of attorney given to members of their team can have that revoked at any time. She advised that this empowers the individuals.

Carol McNulty: asked if **Eva Hamant** believed that these individuals (under supported decision making) couldn't be manipulated.

Karen Van Epps: read a statement of a DDD member that member that has been successful in getting a job, going to college, and making her own decisions. She noted that most of the people that we (the District Central IOC) deal with aren't able to see that level of success.

Eva Hamant: stated that supported decision-making is like being in the family. She noted that it was like when a child goes off to college. Parents provided health coverage until 25, they helped make decisions, and helped support the student while the student was still able to make their own immediate decisions.

Karen Van Epps: advised that down at the legislature there was a mother with her daughter there. She noted that the daughter was bandaged up and unresponsive during the meeting. She relays the mother's statement: "I was told to get guardianship and I did. And when my daughter turned eighteen, she doesn't have any rights anymore." She added that the person doesn't lose all rights.

Carol McNulty: added that they lose the right to vote and make decisions.

Eric Houghtalin: added that his understanding that in certain instances, a member under guardianship could still vote.

Karen Van Epps: advised that was under limited guardianship. She also accounted for a case of a member under guardianship with a serious mental illness (SMI). She noted that the member still lived in his own apartment and kept a job but that if it weren't for the guardianship, the member would be in the streets.

Eva Hamant: added that with this bill, it does not stop guardianship. She noted that people who still need guardianship should still have it.

Sheri Wilhelmi: spoke about her daughter and how she is doing well but that if she were asked what supports she needed that she would say nothing. She noted that her daughter would be perfectly happy sitting in front of a computer, not showering, and devoid of all social interaction. She added that her daughter's idea of nutrition is as many bags of chips as she can eat. She illustrated how her daughter's idea of what she needs is not realistic, healthy, or appropriate. She advised that she caught her daughter in an inappropriate conversation with an online friend and that without interventions, she could be subject to all types of manipulation.

Carol McNulty: added reminded the committee of a member that wanted to live in a large home with a brick fireplace and a pool.



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Karen Van Epps: continued the account saying that when the member didn't get the home she wanted, she exploded. She asked who the team of support would consist of.

Diane Murphy: asked if the member doesn't have a guardianship, will the team argue back and forth until there is consensus.

Carol McNulty: advised that the member would have the final say in any team supported decision making process.

Karen Van Epps: added that in group homes, the provider would likely have unlimited power.

Eva Hamant: argued that most people in group homes would not have supported decision making. She reiterated that this was intended for members that didn't want to go to court. She noted that not every member would have to do supported decision making.

Karen Van Epps: interjected that supported decision making would not require a law.

Diane Murphy: asked who decides who would be on the team.

Eric Houghtalin: advised that the team would consist of the Support Coordinator, the member, providers, and anybody the member (or guardian – if under guardianship) wished to add.

Sheri Wilhelmi: added that if the member were the only one picking the team, that her daughter would pick her furry friends from Comic Con and other people that wouldn't be qualified. She advised that team members could manipulate and/or exploit the member.

Eva Hamant: asked Sheri Wilhelmi if she were in support of the bill.

Sheri Wilhelmi: advised that she is not in support.

Eva Hamant: reminded the committee that this is not for the parents that want to go to court.

Karen Van Epps: advised that if the Judge didn't feel that a member needed to be under guardianship, that they would not order it.

Carol McNulty: accounted her experience with the guardianship process of her daughter. She advised that her daughter had her own Attorney that represented her in the proceedings. She noted that she was present for her daughter's meetings with the Attorney.

Debbie Stapley: advised that letters were sending them letters about guardianship for her family member when she was nearing eighteen.

Carol McNulty: expressed her concern about the potential of abuse that could stem from supported decision making. She advised that she knows that caregivers exploit members.

Karen Van Epps: recounted the story of a DDD member that was 27 years old when his provider took him home and took his money. She advised that the member was killed by the provider because



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he knew too much. She restated her stance that there is no need for a law. She also stated that she resents **John Meyer** because he had been talking about this and adding statements about how incidents like Hacienda could be avoided. She also accounted a case of a member in the MARC Center that choked to death on pizza while his providers were outside smoking. She noted that this member wasn't supposed to have access to food without supervision per the behavior plan and/or annual planning document.

Marlene Riggs: asked about members without anybody (e.g., those in foster care that age out, etc.).

Karen Van Epps: added that this is when the providers have all the power over them.

Sheri Wilhelmi: advised that she is a surrogate and has been taking care of a child since the 3rd grade (he just aged out). She added that she had been fighting with the Department of Child Safety (DCS) to get him on DDD. She advised that she started as a surrogate parent to process the application for DDD for him. She stated that a team would be great but that the only person that knows this child is her.

Karen Van Epps: advised that she spoke with **Robert Beckett**, an Attorney, that is writing a paper for a national organization. She stated that **Robert Beckett** suggested that there are three states that put in a provision that the paid ADH (adult development home) provider could not be a part of the team.

Eva Hamant: added that this was because of the potential conflict of interest.

Karen Van Epps: continued that there are only about ten states that have gone through this (the process of getting a law about supported decision making passed). She noted that Robert Beckett suggested that there was nothing in this law that would prevent anybody from being on a team.

Sheri Wilhelmi: advised that her daughter had a team until she was twenty-six. She noted that it was just her and her husband. She added that she hadn't had a provider in over a year. She noted that having a group is great, but people don't stay.

Karen Van Epps: added that people will move on. She advised that there is nothing that is stopping members from receiving this sort of help and that there's no need for a law.

Eva Hamant: asked why **Karen Van Epps** was fighting it.

Karen Van Epps: stated that it was because the members didn't need it. She added that the SMI group is scared to death because those people are scary.

Sheri Wilhelmi: asked **Eva Hamant** what happens when the team decides that there's no need for guardianship and that goes before a Judge. She added that she didn't think this to be in anyone's best interest. She advised that she has an SMI child living in a group home. She added that if her team



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decided that she didn't need guardianship and that it was okay for her to hang out with people that live on the streets or take drugs (then what do you do?).

Eva Hamant: answered that there would be no supported decision making under guardianship.

Sheri Wilhelmi: advised that her daughter was not under guardianship. She advised that if her daughter were to choose to bring her questionable friends into her team meetings that she would be at a greater risk of making poor decisions.

Eva Hamant: rebutted that surely there were a Judge (and trailed off).

Carol McNulty: advised **Eva Hamant** needed to read the law.

Eva Hamant: asked what about guardianship.

Sheri Wilhelmi: rebutted that **Eva Hamant** was missing the point.

Eva Hamant: advised that either you (the family) decide to do guardianship or you decided to do supported decision making.

Sheri Wilhelmi: advised **Eva Hamant** that she was missing the point. She advised that if you need guardianship and you decide to fight your guardianship and the member decides to fight against it, they could gather their questionable and/or unqualified friends to fight it.

Diane Murphy: asked if the court has determined that a member doesn't need a guardian, would it be safe to assume that the member has the right to appoint any team members that he/she wishes.

Eva Hamant: rebutted that the member would have to have a Lawyer.

Sheri Wilhelmi: advised that if a supported decision-making member were to be arrested for breaking a law, that they would not have any protections as they might under guardianship. Her argument was that with a member with a minimal amount of support would be subject to all of the punishments under the law because they would be considered to be cognizant enough to handle themselves appropriately. She noted that most of the DDD members would not qualify to be under supported decision making.

Eva Hamant: noted that this isn't all DDD long-term care members.

Karen Van Epps: asked what is keeping members from getting supports. She advised that the law is not blocking them.

Eva Hamant: answered that even under limited guardianship, one would have to go to court, and this was a way to avoid court.



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Karen Van Epps: advised that guardianship is a protection of our members. She added that she believed that there are groups that are trying to discourage guardianship. She stated that she knows that the Center for Disability Law does.

Carol McNulty: added that it was likely a cost thing.

Karen Van Epps: advised that there were more pressing needs and that this wasn't necessary.

Sheri Wilhelmi: added that it opens up our members to exploitation.

Karen Van Epps: asked who would be liable if something went wrong.

Carol McNulty: advised that the member would have the final say and that any decision made is on them.

Sheri Wilhelmi: added that this bill doesn't meet a need. She asked how anybody would know that team members weren't a bad guy. She asked if they would need to have a background check or fingerprint clearance card.

Karen Van Epps: read some of the law for the group to understand that the person being supported can revoke supported decisions.

Diane Murphy: had a question about how guardianship worked in Arizona.

Eva Hamant: explained the process.

Marlene Riggs: explained that if a member doesn't have someone actively seeking guardianship, once the member turns eighteen, they are considered their own guardian. She noted that anybody considered their own guardian can do all the things that the average person could (e.g., enter into contracts, start a bank account, get in legal trouble, etc.). She mentioned that there were issues with getting mental health help for members that were not under guardianship.

Eric Houghtalin: asked **Marlene Riggs** if there were a 72-hour hold for people considered a danger to themselves or to others.

Marlene Riggs: advised that there is a petition that will allow mental health facilities to hold anybody for up to 72 hours. Any committed person would have to be admitted under a court order.

Sheri Wilhelmi: stated that even if the member were to be held on a 72-hour hold, there's guarantee that they would face court in time before being released. She stressed the need for Public Fiduciaries and Guardian Ad Litem. She also stressed that the existing bill does not fit a need.

Karen Van Epps: advised that this should start at the schools. She advised that they (the schools) should also note that the member doesn't necessarily need guardianship and that they could help support him/her through education.



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Sheri Wilhelmi: advised that her daughter that isn't under guardianship has been warned that if she starts getting into trouble or stops listening to mom and dad that they will be in front of a Judge.

Karen Van Epps: noted that the schools have been resisting talking about guardianship.

Eric Houghtalin: advised that as a former Support Coordinator, they were told to start the conversation with parents in every quarterly meeting following the member's seventeenth birthday. He also advised that a local non-profit (*Raising Special Kids – raisingspecialkids.org*) offers assistance with the guardianship process and will sometimes even help parents in a one-on-one capacity if needed.

Karen Van Epps: added that members without guardianship could use power of attorneys to secure medical, dental, and other supports without having to apply for total guardianship.

Patricia Sandino: asked if a diagnosis was the only way to be qualified for guardianship or could the person also be deemed incompetent.

Carol McNulty: advised that her daughter was asked several questions by her Attorney to ensure that she needed to prove herself incompetent.

Karen Van Epps: advised that there was a recent grant associated with the groups supporting guardianship.

Marlene Riggs: asked if out of state guardianship transfers into Arizona.

Sheri Wilhelmi: advised that the guardianship does transfer in.

Karen Van Epps: advised that there was a simple process to move guardianship to Arizona.

Eva Hamant: added that a part of the process of guardianship was an annual report to the court and one thing they ask is have you moved.

Carol McNulty: advised that she believed that there was a certain time frame to notify the courts.

Article 9 Discussion

Karen Van Epps: Asked if anybody knew of anybody knew about the progress of the update of article 9.

There were no replies about progress.



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Call to the Public

Sophie Legaspi: had no updates but invited IOC members feel free to communicate with her if they have any needs.

Vera Kramarchuk: had no updates but invited IOC members to reach out.

Committee Member Report

Eduarda Yates: wants to add a conversation about SB 1552 and how special education is costing the schools.

Diane Murphy: advised that she has a link to the bill that she would send to Eric Houghtalin. She asked him to forward it to the committee.

Eric Houghtalin: advised the committee that he already sent the email with links to the draft of SB 1552, SB 1552 tracking webpage, and the link to the article that **Eduarda Yates** brought in for the members.

Discussion, Review, & Possible Action on Committee Membership

Eric Houghtalin: reminded the committee to send him leads for new members and organizations that might be good sources for new members.

Carol McNulty motioned to move into executive session.

Andrea Potosky seconded the motion.

There was no discussion.

All available members voted yes to move into executive session. No members abstained or voted no.

The public session ended at 11:29pm.



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Incident Reports and Behavior Plans

IOC Members took incident report packets with them prior to leaving. There was no discussion with the Quality Improvement Manager regarding the members or incident reports after the public meeting ended.

The incident reports included **704** closed and **128** open for a total of **832** total reports for the September meeting. An email was sent to the District Central Quality Improvement Manager to inquire about delivering the incident reports to the committee, but it was not replied to by the end of the meeting.

Type	Open	Closed
Accidental Injury	22	136
Deaths	8	0
Emergency Measures	5	52
Human Rights	4	0
Legal	6	3
Medication Errors	7	93
Missing	14	3
Neglect – Potential & Imminent	18	6
Other Abuse – Sexual, Verbal, and Emotional	13	1
Other	17	399
Physical Abuse	10	3
Property Damage	4	0
Suicide	0	8
TOTALS	128	704

IRs were equally divided among the members in attendance as they chose to take them. There was some discussion of individual incident reports among member and DDD staff in the executive session.



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Adjournment

Carol McNulty motioned to adjourn the meeting.

Sheri Wilhelmi seconded the motion.

There was no discussion.

All available members voted yes to move into executive session. No members abstained or voted no.

The meeting ended at 12:23pm.

The next District Central IOC meeting will be held on March 23, 2020 at 10:00 am.

(The meeting ended at 12:23 pm)