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**Advisory Committee Meeting Minutes**

**January 12, 2019 11 a.m. – 3 p.m.**

**Disability Rights Washington, Large Conference Room**

**315 5th Ave South Suite 850 Seattle WA 98104**

**Members present**: Ross Damm, Ed Holen, Sorretie Jaro, Jamie Kasinger, Rocio Lopez, and Mike Raymond

**Members unable to attend**: Tony Hall, Ky Ly, Willie Medgard,

**Staff present**: Andrea Kadlec, Beth Leonard, Tim McCue, Lisa Robbe, Betty Schwieterman, Noah Seidel

**Accommodation**: Kathy Easton

**Guests**: Chris Gagnon, Department of Commerce and Lei Mydske, potential new member

**Meeting called to order:** Mike Raymond called the meeting to order.

**Introductions**: Everyone introduced themselves and where they are from.

**Minutes** read by Lisa. Ed moved to accept minutes as read. Sorrettie second.

**Motion carried by voice vote.**

**Hospital Report**. Some people with developmental disabilities end up in hospital settings and then have nowhere to go. Providers may take people there after they can no longer support people in the home. Parents may take to hospital because needs aren’t being met. There may be a behavioral issue and someone may be brought to the hospital even though there is no medical issue. The report highlights this issue and gives recommendations to the legislature so we can get more support for people, so they don’t get stuck in the hospital. Recommendations: 1) DDO work with the Developmental Disabilities Administration (DDA) to discover how big this issue is, and so that we can get an accurate picture of where, when, and how and why this is happening. This will help us come up with solutions. 2) Invest in community resources to prevent crisis from happening, so that people aren’t brought to the hospital. This might prevent the need for people to go into the hospital. Also this could help train providers so that there is a stable workforce and also so that providers have enough knowledge to meet needs of individuals. 3) Provide more housing in the community, so people don’t have to stay in the hospital for long periods of time, but rather have a place to go, and so that people have a place to go in crisis that is really short term.

**Hospital report feedback**: Committee: Have you talked with DDA about getting data? Answer: Yes, we talked to the hospital association and DDA but neither one had data to share. We will continue to work on this. Committee: We need more respite beds to deal with these situations where staff are trained. Thank you for doing this report. This opens a number of larger issues that need to be addressed - 1. We don’t have a crisis response system in place for people with developmental disabilities. Responders don’t know how to work with people with developmental disabilities. People with developmental disabilities can’t access mental health services. Can the DD system look at how services are offered on the community intensive behavioral system and supports waiver (CIBSS) waiver? Some strategies there may be applicable here. How do we bring this discussion out in the light? Let’s jump start work on this issue. We should get this going. Betty: This report focused on adults. We did that because the adult system has different rules for service delivery. We have also been working with families with children. These families use emergency room and are in and out of the emergency room until they are really in crisis. Services are disjointed and siloed so it is hard to move from one to the other. It is hard to move from voluntary placement to CIBSS, or enhanced respite. So we are looking at a similar report for kids. We see similar and very traumatic things that happen to kids and their families. Committee: Is this every hospital in the state? Or does this happen regionally? Where does this happen? Beth: All regions, big cities and rural communities. We don’t have enough data to give specific information but appears to be happening around the state. Betty: We are checking in with people after they get out of the hospital, to make sure they get supports so they don’t have to go back.

**Legislative Agenda**: Noah talked about the recommendations to the legislature. The DD Ombuds has three recommendations:

1. Identify and close gaps in mental health services for people with developmental disabilities.
	1. Proposal: Create a legislatively mandated workgroup to examine gaps.
2. Invest in quality community supports and services for children and adults with developmental disabilities to reduce use of crisis services.
	1. Proposal: Increase direct service worker wages.
	2. Modify state law to clarify APS definitions. Give APS authority to share information with law enforcement and with DD Ombuds. Modify abuse registry structure.
	3. Fund investigations to protect people in supported living.
	4. Direct DDA to remove barriers to utilization of behavioral supports for children and adults who reside with their parents.
	5. Increase capacity of crisis and transitional placements for individuals with developmental disabilities.
3. Secure rights of people who use DDA services
	1. Proposal: Spell out rights of people who use DDA in statute. Equalize timeline for notice of termination of residential services and require transition planning. Provide written notice to clients when a provider receives provisional certification or is decertified.

The Rights bill has a prime sponsor, so it will be heard in this legislative session. Rep. Kilduff in House. Leadership of Senate is deciding who will sponsor.

**Questions**: Wages for workers went up last year. Was this successful in addressing these issues? We need performance measures. Can the workgroup look at this? Can we track that increased funding makes a difference? Betty/Noah: Gave suggestions on ways this could be tracked. Committee: Increased funding does make a difference. We have seen this, with providers. Also, we have issues getting our needs met. Committee: Are there issues with case managers? Does DD Rights bill address this? Noah: We can look at that issue more in depth, but that is not brought up in this specific bill. Lisa: What is the issue with the abuse registry? Betty: One of the problems is that the registry is you are on or off no matter the severity. For example, there may be a minor issue at age 15 in foster care and one can never get off. Or, an individual may have staff and they want that provider, and the provider’s issue for being on the registry was minor, and they could work well with this person.

**Other legislative issues of interest**:

Proposal for employment supports involved for students at age 18. This is being brought forward by the Community Employment Alliance (CEA). Healthcare for Workers with Disabilities: There is a work to remove the cap, so that people can keep their jobs and make money without losing Medicaid/Medicare. This is a big issue for people with disabilities, especially with the minimum wage increase.

**Regional Updates**

**Region 3**: Noah - Monitoring Clallam County: Adult family homes and supported living. People have been in their homes for multiple years, very stable. People use community engagement and other services to be in the community. Clark County: Visited supported living. People live close together- very clustered. Multiple complaints. Thurston County: Visited supported living. People were happy with where they live. There were questions about representative payee services. Pierce County: Visited supported living. Questions about representative payee services. Complaints around employment. Rainier School: Did a tour with the Department of Commerce. Received updates on certification as of January 7, 2019: intermediate care facility A: Decertified pending resurvey. Intermediate care facility C: Decertified pending resurvey; Intermediate care facility E: certified. Western State Hospital: Received tour and met with administration. Visited residence at Habilitative Mental Health (HMH) and job sites. Active treatment: Fashion center, recycling, etc. These work sites are for people in the HMH unit. They are paid federal minimum wage. Noah did many trainings recently and helped people with complaints: people stuck in hospitals; rep pay info; DDA eligibility; transfer/discharge/ lack of staffing privacy, choices, activities, meaningful day.

**Region 2**:  **Beth** - SL Start became Aacres – 40-60 people in AAcres King County. We have been visiting those individuals. Aacres King County received citations for health and safety concerns. They decided to give up their certification instead of being decertified. The individuals they served are getting new providers. We are visiting people as they transition. Fircrest: People coming in from Rainier moves. Working on complaints.

Committee: It is so traumatic for people in the RHC to lose people who move, and it is so hard to move. This causes people to go into crisis. It is one thing when someone is in crisis and has to move, but it’s another when someone has to move because of paperwork (active treatment requirements). People may have been at an RHC for most of their lives. They should have a voice in where they move. Decisions are being made because of money instead of choice. This is something we should look at more closely.

**Andrea -** Camelot is a provider who provided ICF level of care and decided to change to supported living, which means about 20 people are moving. So we are going to follow their care as they transition.

DDA has run out of their Money Follows the Person funding and we are working with individuals who are transitioning to the community, so we will follow this. Working with an individual who is undocumented and was dropped off at a hospital. No known family in the area. Not clear what will happen to him. Working with individual who had supported living services terminated because he couldn’t get needs met. He is now at Fircrest.

DD Ombuds helped organize and attended 10 trainings on trauma informed advocacy for people with disabilities.

**Region 1: Lisa -** Hospital issue is big. There are people who have been in the hospital for months. There is an individual who has been restrained for over 20 days. These are people in nursing homes and adult family homes. There are people waiting for beds at Eastern State Hospital. There are people ready to get out and no place for them to go either. People in the hospitals are not always contacted by the case manager. Hospital staff also complain of lack of contact from DDA administration.

Case management concerns: Learning that case manager quit after not being able to get a hold of a case manager for months. Case manager may not have information about how to communicate with the person and assumed the person would not be able to communicate.

Visited HMH at Eastern. Good interaction with staff on the unit. They want Tim to do a presentation and want the Ombuds to come back. Active treatment looks very different here. There is only subminimum wage employment here.

We are getting complaints that are a result of visits that we have done in the past. Sorretie and Lisa presented to guardians ad litem about the DD Ombuds. Sorretie talked about what it is like to have a guardian and how important it is to listen to the person.

**DD Ombuds’ Contract -** Disability Rights Washington won the contract to administer the DD Ombuds Program in May of 2017. This December we got notice that the DD Ombuds was going to be put out for bid again. We were surprised because state law says that once the program is designated, it cannot be revoked unless we did something wrong or couldn’t do our job. We wrote to the Department of Commerce and attended the stakeholder meetings. We have talked to people we serve and people we work together, people who are allies in our advocacy. This has caused a lot of stress and concern in the disability community. We are creating relationships and providing services and people are worried about whether we will be able to still do that. We have confidential information, and we want to assure people that it is safe and won’t go anywhere. We are worried that this impacts our ability to do our work. We have worked hard so people trust us and feel like they can bring concerns to us. We don’t want anything to jeopardize this. We have a letter of support circulated by the disability community. We are grateful for their support.

Department of Commerce: Commerce has drafted a response letter and will get that to the DD Ombuds next week.

Committee raised issue about protection for students with disabilities in school, after an incident where a teacher dragged a student with autism and it was caught on video. Advocates in Washington are working on restraint and isolation issues.

**Annual Report and Service trends** - Activities for state fiscal year (SFY) 2018.

**Outreach, training and education and information on rights and responsibilities**

* DD Ombuds reached 2129 people at 106 training and outreach events
* Provided detailed information and referrals to 43 people
* The DD Ombuds produced 2 videos in seven languages

**Complaints**

* 345 people benefitted from individual and group complaint investigation and resolution
* The majority of complaints concerned autonomy and exercise of rights, followed by issues with individual care, abuse, neglect and quality of life.
* Began receiving more complaints about people stuck in hospitals.
* Began tracking barriers for in home supports for children and youth.

**Monitoring**

The DD Ombuds made 348 monitoring visits to

* Certified residential settings
* Licensed residential settings
* Cottages and programs at Residential Habilitation Centers (RHCs)
* Voluntary placement services for children
* Adjusted monitoring schedule to visit people served by providers who were decertified or under provisional decertification

**Systemic issues identified include**:

* Systemic report: Diverting Crisis
* Systemic report: Stuck in the hospital
* Staff shortages and staff turnover in certified residential settings
* Access to activities and social engagement
* Access to behavioral supports and access to mental health care
* Simplification of the eligibility process for DDA services
* Address abuse and neglect, especially procedures for handling physical assault by one roommate against another in a residential setting.
* Sexual assault – improving the response

Committee: Was a teacher in Seattle fired and people were upset because she was good with kids with disabilities? What does your program do for these issues? Andrea: We work with Office of Education Ombuds, and Open Doors for Multicultural Families. There are advocates who are working on these issues. Committee: New Issue - Independent Provider Records Management– new program developing. Make sure that as this happens, the people are supported and not impacted by problems that arise when there is a problem and person suddenly loses independent care provider. Make sure there is some sort of protections in place. This agency will also manage electronic visiting verification. Make sure this process is respectful for people with disabilities. Betty: Will be good to work with the agency that is chosen, and get in there early and talk about consumer rights and consumer education and make sure people know how and when to refer to the DD Ombuds. DDC advocated for agency that really listens to people. Could build on this and make it clear this is an expectation for whatever organization is chosen to do this. The hope is then case manager will have more time to do case management.

**Membership Elections**

Angie Flores: Wants to be an advisory committee member. Says the DD Ombuds changes people’s lives dramatically and that we speak out when no one else does. **Motion:** Sorretie motioned that Angie become a committee member. Jamie seconded. All voted yes. **Motion carried by voice vote.** Lisa will call and let Angie know.

Lei introduced herself. Lei is involved in Women with Autism and runs an Autistic Self-Advocacy group. Lei is a parent of an individual with a disability. A vote for Lei will be held at the next meeting.

**Officer Elections:** Tim reviewed the office positions open for elections:

Chair: Currently Mike. Runs meetings. Calls meetings to order and adjourns meetings. Makes sure meetings go by agenda.

Vice Chair: Currently Ros. Assists president and fills in for the president if the president can’t fun a meeting.

Secretary: Currently Ky and Willie. Takes minutes at the meeting and reviews minutes at the next meeting.

Committee must decide if people run two years in a row.

**Motion:** Mike motioned so people could run two years in a row. Rocio seconded. All said aye. **Motion carried by voice vote.**

**Chair -** Mike is running for chair again. Mike said the reason is that since he has been on this board, he has done a good job and tells people what we do. Please vote for me. Jamie would also like to run for chair. Ross would like to run for chair. Could help get things done and is very involved in the community.

Advisory Committee members voted. **Mike Raymond elected as Chair.**

**Vice Chair -** Willie wants to run. Ed nominated Jamie. Ross wants to run.

Advisory Committee members voted. **Jamie elected Vice Chair**.

**Secretary -** Jamie nominated Rocio. Jamie nominated Sorretie. Both accepted their nominations.

Advisory Committee members voted on ballots. The vote was a tie. **Rocio and Sorretie accepted and will share the position.**

**Other Issues -** Committee: Eligibility issues, especially around IQ. Can we look at changing the law or the eligibility requirement? This discriminates against people. Maybe we can bring this up with the state legislature. Andrea: Not a specific bill – but we are looking at eligibility issues for DDA. DDC: This is a big problem. There is also an underlying problem that people who are eligible still don’t get services. Our waiting list is 14,000 people long. We need to make sure if people are eligible, that there is money for them to get services. Lisa: There is a new movie out called Intelligent Lives that shows IQ is not a good measure.

**Next meetings**: April 27; July 13; October 12

**Debrief**: Committee: Today was accessible. There was good information. Anything we could do differently or better? Committee: No. You are working on lots of issues.

**Adjourn**: Mike adjourned the meeting.