

LCPD Meeting Minutes

Nov 2. 23

Recorder: Mitchell Kohler

Roll call: Mitchell Kohler, Gina Pola-Money, Lisa Thorton, Connee, Anita Bennett, Shannon Wilkins, Kristen Cornia (DSPD), Marian Furst, Audrey Snyder, Christi Carpenter, Jennifer Miller-Smith, Janis Ferre, Ashley Donham, JoLynne Lyon, Anneli Smith, Jenny, Esperanza Reyes, Tyler Black, Stephanie Roach, Everette Bacon

Minutes:

Welcome – Anita Bennett

Introductions

- Everyone introduced themselves.

Approval of the minutes

- Minutes approved with the correction that Anita Bennett was present at that meeting.

Concerns:

Caregiver Compensation Policies and Implementation

- Lisa asked Kristen (DSPD) what kind of input she would like from LCPD and other organizations.
 - Kristen (DSPD Finance Director) said they are still looking for input. Over 400 comments so far. Any input they receive will be looked at.
 - Lisa mentioned that both the legislative sponsors of the bill had comments. Rep Provost said she would like to see the program move forward with as little bureaucracy as possible so that families would not have to jump through hoops. Another meeting with Rep. Provost and Harper may need to be set up so that they can supply their input.
- Lisa asked Kristen if it would be helpful for professional organizations that treat many of the clients already on DSPD for their input.
 - Kristen said that they have already been in contact with such groups. But any other input is still very helpful.
 - Lisa and Anneli expressed concerns that the bill would not cover individuals in the

middle, those not to the extreme but who still need substantial care. Families may be forced between keeping a job or staying home to care for their children. This will be **many** families' situation. "The tier system is causing people to panic."

- Lisa mentioned a fix could be that an adult child who is not in a residential placement would qualify for tier 3.
- Furthermore, there are no considerations for assistance for people to find caregivers.
- Jenny said school aged children should not be automatically disqualified from tier 3.
It shouldn't be an age issue.

- Jenny asked Kristen how the DSPD will ensure that there is no overlap of services if time sheets are no longer being used.
 - Kristen said it is something DSPD is working on, she believes the monthly report system they're working on will pass Medicaid approval.
 - People really wanted to move away from time sheets.
- Lisa asked Kristen why the tiers were based off the severity of the child.
 - "Everything has to be based on the health and safety needs of the individual" was her response.
 - Anneli noted that for many families, supervision is the number one thing that keeps them safe.
 - Kristen took note of that.
 - Lisa emphasizes the core issue is that the families who don't qualify for tier 3 or tier 2 will face burdens.
 - Anelli said it doesn't come across as very flexible.
- Kristen says to keep submitting comments.
- Janis says time sheets don't necessarily have to be difficult.
- Kristen asked if we would prefer the time sheets tracking.

- Lisa said she would, as the tier system only benefits the most severe cases.
 - But it's the inflexibility of the tiers that's the real problem.
- Kristen asked for any more comments and input before we move on.
 - Lisa summed up that the tier system as it stands just isn't adequate for the majority of families.
- Everette joined into the meeting and took over for Anita.
- Lisa and Anelli brought up the concerns from last meeting about the guardianship bill.
 - And with the supported decision-making bill.
 - Lisa was at a committee meeting that included lawyers and judges. She and Anelli went through it with them and pointed out many of the issues with it.
 - They asked that an exemption be made for those with court-ordered guardianship, with a lifelong disability, and incapacitated before the age of 18.
 - A vote may be held at the next meeting to decide whether LCPD will support Lisa and Anelli's effort.
 - Aubrey clarified that the bill would not automatically let those under Guardianship make their own decisions. Another meeting with the Disability Law Center would be helpful for clarification.
 - Lisa read from the most current bill.
 - Anelli said the problem lays squarely with some of the language of the bill that would allow children to make potentially dangerous decisions without Guardianship consent.
 - Aubrey said she agreed with the Disability Law Center's belief that this is the dignity of risk individuals maintain and to agree to disagree. She again proposed that we meet with the DLC again so everyone can have a full understanding.

- Everette said that another meeting would not be beneficial, at this point we've listened to all sides.

Round Table

- Everette mentioned that this is voting month. A new system is in place for those with disabilities, there is now an electronic mail ballot. Call County Clerks to gain access.
- Marian (Rare and Undiagnosed Community) is interested in finding out issues people have in accessing and paying for care. Looking into alternative funding schemes for gene therapy.
- Jennifer mentioned that the definition of disability may be changing at a federal level.
 - Sending this info to Everette.
- JoLynne mentioned "IDRPP is looking for family members/self-advocates to serve on our consumer advisory committee."

Calendar

Adjournment