

LCPD Meeting

September 7, 2023

12:45 pm – 2:00pm

Present:

Gina Pola Money, Janet Wade, Anita Bennett, Jennifer Miller Smith, Anneli Smith, JoLynne Lyon, Mrian Furst, Ashley Donham, Aubrey Snyder, Farrah Edwards, Jenny Koftinow, Stephanie Roach, Kari Teague, Sylvia Lam, Stacy Stanford, Rich Foster, Mitchell Kohler, Tina Persels. Excused: Mallory Poole, Everette Bacon.

Anita started the meeting by welcoming everyone.

There are several concerns in rule changes and pending legislation that have been noted by LCPD.

Guardianship:

Anneli and Lisa shared that parents who currently have guardianship are concerned about pending changes that may impact the safety of their adult children and leave them open to exploitation. There are inconsistencies in the law that need to be clarified. Lisa stated that the Elder Law Committee is also concerned.

In order to work on understanding the issues and clarifying the law Lisa and Anneli will form a coalition along with members of the Elder Law committee. This will be a separate coalition from LCPD and will report back to the LCPD on their findings and actions at the October meeting.

Thanks to Lisa and Anneli for their work on this important issue.

Stephanie asked if Supported Decision Making was in place in Utah. Lisa replied that it is not currently in place.

There are concerns about how to measure contractual capacity. The Disability Law Center is active in working on Supported Decision Making.

Caregiver Compensation Policies and Implementation:

Lisa commented that Caregiver Compensation is in place, but we have had no contact with DSPD regarding input on policies. Last year the Caregiver Compensation coalition worked with DSPD to provide input on policies. Clarity from DSPD would be helpful.

Jenny reported that there may be a three-tier system for compensation and wondered how that would be individualized.

Janet replied that there had been discussion last year about a three-tier system and input was given by the Caregiver Coalition.

Janet mentioned that she had invited Tyler Black (DSPD) at short notice to this meeting. She will invite him to the October meeting to give more information on any changes in policy.

Deanna reported that there is a system – My steps - [Welcome to MySteps \(utah.gov\)](https://www.utah.gov/MySteps) This web site provides information to families on the wait list.

Services for Technology Dependent Young Adults:

Tina and Gina spoke of the lack of services for those on the Tech Dependent Waiver and the Medically Fragile Waiver such as fair pay for Caregiver Support if even offered. The Technology Dependent Waiver currently does not have a system in place to provide services for this population that are equitable to those that have services through DSPD, especially for those that have transitioned into adulthood and are no longer receiving services through the education system. The waiver is administered under Long Term Care in Medicaid. Individuals that would like to be out in the community do not currently have access because they need to always have a nurse with them or a parent to manage the airway. The Nursing services provided as respite are not enough to support the individual in any type of Day Program or other community activity including Voc. Rehab services. These individuals require a nurse to be always with them and programs/agencies including DSPD do not fund currently due to the skilled need of the individual. It is an inequity in services for those that need these extra supports.

Tina spoke about meeting Mike Mower from the Governor's Office at the LCPD reception. That meeting led to the formation of a stakeholder group. This issue is now #6 on Medicaid's Budget priorities.

The Stakeholder group would like the creation of a 1915i waiver. This would allow the request of a set of services such as a nurse, employment services and other services to support these young adults.

Nate Crippes from the Disability Law Center is partnering and working on this. There is a need for a legislative champion to help and create legislation.

Round Table:

Jennifer Miller Smith gave information on Federal Issues on changes to Section 504 [Section 504 Rule Update Important Change to End Disability Discrimination - Caring Across Generations](#). Jennifer suggested that members try to keep an eye on changes to Disability Laws in Washington.

Jennifer also mentioned legislation that will make it illegal for landlords to discriminate potential renters who have housing vouchers. Nate Crippes from the Disability Law Center is working on this. [Fair Housing - Disability Law Center, Utah](#)

Stacy reported on the mass disenrollment of Medicaid recipients. Medicaid participants did not have to renew eligibility during the pandemic. Unfortunately, many Medicaid recipients are being disenrolled. Utah has the highest rate of disenrollment. A coalition is working on this. There are concerns about separating Medicaid eligibility from Health and Human Services.

Farrah stated that DWS does train their eligibility workers in understanding disability issues and customer service.

Stacy also reported that they will be hoping to pass a Co-Pay Accumulator bill again. It narrowly failed last year. This will mean that prescription vouchers can be used against the co-pay. This is not allowed at the present time.

Aubrey Snyder mentioned in the chat that IDRPP at Utah State University is working on information and advocacy for funding the Early Intervention Programs.

Janet motioned to adjourn.

Gina Seconded

All approved.