

LCPD minutes

February 3, 2020

Start time 12:30 pm

Beehive Room State Capitol

Present: Please see attached sign in sheet (Please correct spelling and add your name if you were present and I did not hear your name called)

Due to the storm the meeting was held over a conference line.

The meeting was opened by Joey Hanna, Chair, with welcome and introductions. Joey thanked the members for attending the Reception and Disability Day. Joey remarked on the number of legislators present and that she was able to talk with her representative.

Members were asked to comment on any bills or issues that they would like to address before Jennifer Miller-Smith presented the Bill tracker.

Q. Arlene Gunderson: What is the approach for people who are linguistically and culturally different? Matthew Whappett explained that there is a Concurrent Resolution: Concurrent Resolution Encouraging Cultural Intelligence and Linguistic Competence.

The Center for Persons with a Disability (CPD) drafted this. It encourages state agencies and non-profits to be more pro-active in developing plans in linguistic action and cultural responsiveness; encourages Social Service Agencies to consider accessibility, sign or physical; encourages legislative weight to develop more specific plans. The resolution does not mention all aspects of ability or culture.

Andrew R. One of the committee members did specifically ask if the resolution intended to include ASL and other non-spoken languages in its scope and the answer was yes. The legislation is not ideal – no specific mention of populations as they intended but it does capture ability.

Sachin Pavithran: It was the Intent to keep it broad as they didn't want to leave out any groups.

Arlene: As a group we need to be supported. What about those who have different needs? What kind of representation for those people who may have needs?

Matt: Part of the issue is that we have reached out to various deaf organizations and at disability day did invite deaf orgs to participate. They declined.

Janet: Welcomed Arlene to the group and invited her to participate in LCPD meetings.

A question was asked on what makes up a quorum. A quorum is 90% of members who are present at the meeting.

Motion by Jennifer to support the resolution:

Seconded Teresa Larson,

All in in favor

No Abstentions. No Nays

Bill Discussion:

Please go to https://docs.google.com/spreadsheets/d/1Qs3QsBCziPEWVGpa-d7rvxU3V6leStCRAu_zL-mQW34/edit#gid=0 to access the Google doc and access the bills

The tables below document the bill or funding request, the discussion, and the position of the LCPD. Only those positions voted on by the LCPD membership can be discussed with legislators as being supported by LCPD.

Bill Title Sponsor	Discussion	Member vote	Position
HB35 HB 32	<p>Andrew Riggle: Quick overview on conversations on HB 35. This is one of Rep. Eliason’s mental health bills. Steve wants to study in-patient bed capacity and the need for additional in-patient beds at the State hospital and in-patient beds in private facilities for transitioning out of the State Hospital.</p> <p>Creates a community teams that are physically prescribed as Social Workers that act as a hospital without walls for those with persistent mental illness. Urban areas and also create mobile crisis teams off the Wasatch Front.</p> <p>The Disability Law Center (DLC) have been in extensive conversations with Rep. Eliason and provided input on HB 35 and a lot of explanation. What we have said is that we have concerns about a system or approach focused on the immediate crisis and stabilization following crisis. Without paying attention or putting resources in place after stabilization. What happens after the initial crisis and stabilization? What resources will be available to reduce the likelihood of them returning to in patient settings? The DLC proposed language to Rep. Eliason that he is open to and we are waiting to see if the new language is</p>		Follow

Bill Title Sponsor	Discussion	Member vote	Position
<p>HB 210 Rep. Ward HB 214</p>	<p>included. Basically proposed: If you are going to do this right need to look at both sides of the system. In patient crisis and long term community based services. HB 32 and HB35 go together but most of suggestions were on HB35. HB35. A committee will study the need of increased bed capacity. Forensic beds. It also proposes a basic program where an organization can apply for the money to form treatment teams. Teams specifically for people transitioning out of the State Hospital. Also provides additional crisis team. Jennifer – Eliaison would appreciate our support. Has DLC taken formal position? No position from DLC as not sure of the final language. Matt: the DLC worked on these bills so a wise course would be to watch.</p> <p>Joey Hanna: Stated that she would like to see more language on supportive services. Nothing around community based care. DLC happy to share the suggestions that we’ve made with everyone. Andrew will send those recommendations to Janet. We will follow B35.</p> <p>Jessie Mandle: Rep Ward Insurance coverage for children amendments. This bill would require the Department of Health to seek a federal waiver to provide continuous coverage among other provisions.</p> <p>HB 214, Insurance coverage modifications. Jessie will send Janet the Fact sheet on these two bills to send out to members for review. (Attached to this email).</p> <p>Andrew Riggle added information About HB 214:</p> <ol style="list-style-type: none"> 1. A limit on out of pocket costs for prescription drugs. 2. Also has a piece that says if a person has one of 4 genetic conditions, one is Cystic fibrosis and wants to get or is pregnant, Medicaid will pay for genetic testing to see if child carries the disorder. If the result comes back positive Medicaid will pay for IVF so that child is born without the condition. 	<p>Vote combined with Baby Watch Funding Request</p>	<p>Support</p>

Bill Title Sponsor	Discussion	Member vote	Position
Rep. Ward	<p>3. Previously when drug companies would give a stipend they weren't able to use that contribution to count towards the deductible.</p> <p>4. DLC has yet to take a position as there is a need to have an internal conversation to puzzle things out.</p> <p>5. There are conversations with Rep. Ward to find a way to separate the bill into two pieces but so far no progress.</p> <p>Stephen – looking at the bill seeing the 4 tests that can be done. Is it limited to those 4 or is it going to be opened up? The way that reads the plain text is that it is limited to those 4?</p> <p>Julia Pearce: Andrew do we know why? Andrew no.</p> <p>Joey Hanna: Follow this legislature and have someone who knows about this to explain it next week. Or we could have Rep. Ward to present. Andrew. Will follow up to ask Courtney or Rep Ward to present on the bill.</p> <p>No vote on position until further explanation.</p>		
HB 219 Rep. Dunnigan	<p>Mental Health Amendments: Stand alone to direct Medicaid to request a waiver from the Centers for Medicare and Medicaid Services (CMS) to allow Medicaid to pay for in patient mental health stays longer than 15 days in facilities larger than 16 beds. Currently Medicaid is not allowed to pay for stays in facilities larger than 16 beds in a month. You will hear from the hospital association that it is important to keep someone in the facilities longer than 15 days. In order for the facility to be economically sustainable it needs to be larger than 16 beds. DLC's concern is in response to system's history of institutionalizing people. Concerned that this might be a step back in that direction. Might limit the building out of community based system.</p> <p>The argument is: If we had a functioning community based system we wouldn't need to invest in a more extensive in patient system. If there is a legitimate need at a minimum we need some parameters and limitations around the facility.</p> <p>Jean Boyack- Is this associated with foster care? Andrew doesn't believe so. But it might be a group that is impacted.</p>		Follow

Bill Title Sponsor	Discussion	Member vote	Position
	Does this committee want to take a position on this bill HB219 Jennifer moves to follow the bill.		
SB 39 Senator Andregg	<p>Andrew: SB 39 Senator Andregg: Affordable housing amendments. Provides 20 mil to one-time \$ in support of additional affordable housing units. 10mil ongoing of rental assistance. Conversations DLC are hoping for is that with all of the work going into the Mental Health system that there would be a way to incorporate additional resources for supportive housing. Also see if we can work with him to get a portion of the resources.</p> <p>DLC would like to talk to Sen Aderegg about the fact that private developers can't serve without government help. Folks who earn 30% and less are not able to make things work. That is the portion of the market that needs support. "Deeply affordable" housing into the bill.</p> <p>Matt Wappett: Aging has brought this up. It is a huge issue. Andrew Riggle: This is an opportunity to get something done.</p> <p>Sen Anderegg is wanting to get something to get done and if we approach him and talk about this there is a chance we might get something done.</p> <p>Joey asked if we could get more information. Joey will contact Sen. Anderegg. Utah Housing Coalition is working the bill heavily.</p>		More Information needed
	<p>Lori Packard asked about the nursing bill for children with complex medical needs. This is a medical bill sponsored by Rep. Ward. Lori Packard explained that there is conflict with nurse care practitioners and families who wish to be allowed to give skilled nursing in the home such as G Tubes and Trachs. The Independent Support Coordinator Association had a meeting with UDBC. Several families and providers and nurses were in attendance. They explained the oversight that was needed for someone to take over those tasks. Continues to be concern. E.g. might be a host home parent with a trach and having limitations for nurses coming in at needed times. This might jeopardize services.</p>	<p>Motion: Lori Packard for LCPD to support this bill Seconded: Stephen All in favor No Abstentions No Nays The motion carries.</p>	Support

Bill Title Sponsor	Discussion	Member vote	Position
	<p>Joey asked if Libby knew anything. Lori would highly support this. It causes a lot of problems to provide services. Families need to have the flexibility to hire and train people who can do these tasks. However the nursing act is saying that this is a skilled nursing task.</p> <p>Joey Definitely see this a lot in Utah Parent Center. Think we should watch for this legislation to come out. May have to do this through email. When it comes out we should support it based on families not being able to access home and community based services.</p> <p>Jennifer: We do not have to have a bill number.</p> <p>Joey – get in touch with Ward and ask him. Place holder home and community based services:</p> <p>Lori – make a motion to support this bill</p> <p>Stephen Second.</p> <p>All in favor.</p>		
<p>HB 86 Rep. Craig Hall</p>	<p>Adult Autism Treatment Program. Creates a program within the Dept. of Health for treating adults with autism</p>	<p>Motion: Janet Wade for LCPD to support this bill. Seconded: Anita Bennett All in favor No Abstentions No Nays The motion carries</p>	<p>Support</p>
<p>HB 106 Rep. Perry</p>	<p>Rare disease advisory council. Matthew Whappett: Good bill – good idea.</p>	<p>Motion: Matthew Whappett for LCP to support this bill Seconded: Jennifer Miller-Smith All n Favor No abstentions</p>	<p>Support</p>

Bill Title Sponsor	Discussion	Member vote	Position
		No Nays The motion carries	
HB 205 Marsha Judkins	Education Bills: Jan Ferre sent these bills to follow.		Follow
HB 77 Rep. Thurston	Education Funding Amendments		Follow
ABLE accounts	Jennifer Miller-Smith asked about the ABLE account legislation by Jennifer Daly-Proust. Andrew Riggie that there is a savings account for people with disabilities: ABLE account. Rep Daly Provost has abandoned the bill as Utah's can access the ABLE accounts through other states. She is not pursuing the bill this session.		
SB 44 Sen. Hemmert Rep. Thurston	<p>This is one of the mechanisms to provide supports to individuals who might end up in a facility as their only option. This comes under the settlement. Dept. of Health doesn't need Leg permission to apply for the waiver. Matthew Wappett explained that what this bill does is that any appropriation the legislature makes is not subject to the 85%-15% split in current H&CB waiver. 15% to preventive services like respite. Any funding for this would be independent and dedicated only to it.</p> <p>Matt: although it is wrapped in the settlement is there any advocacy we need to do? Andrew – Yes. To the extent to which we are able. My understanding that the budget request was for 4.5 mill</p> <p>This also falls under the DOH, DHS & DWS funding request</p>	<p>Motion: Matthew Whappett for LCP to support the bill and funding request</p> <p>Seconded: Julia Pearce All in Favor No Abstentions No Nays The motion carries</p>	Support

Agency Requests	Discussion	Member vote	Position
<p>DOH 436 More Baby Watch Clients</p>	<p>Kelsey Lewis Commented on the funding request. The Baby Watch Early intervention local programs continue to be concerned that they are only serving 3% of Birth to three pop. National average is 5%. Some programs have had to limit direct service provisions. Last year the programs lost 1 mil in revenue because of high number of kids who were Medicaid eligible but who dropped off the roles. When Medicaid funding is lost no extra money is allocated from the State. Children are getting fewer services and therefore outcomes will drop. The DOH is asking for 1,545,200 in ongoing funds. Kelsey also mentioned the Medicaid bill that Jessie Mandle reported on earlier in the meeting</p>	<p>Motion: Jennifer Miller-Smith moved for the LCPD to support the Baby Watch Funding request and also HB 210 Seconded: Matthew Whappett All in Favor No Abstentions No Nays The motion carries/</p>	<p>Support</p>

DWS	2 mil request for community based employment. Think this is necessary for Disability Services: Community Based Employment. Joey Hanna explained that this was necessary for providers to become compliant with settings rule.	Motion: Janet Wade moved for the LCPD to support this funding request. Seconded: Lori Packard All In Favor No Abstentions No Nays The motion carried	Support
DOH	Compensation and ISF Exception for Children's hearing Aid account. No position taken. More work to do on this request.		

Motion to Adjourn

Matthew Whappett

Seconded:

Jennifer Miller-Smith

All in Favor, No Abstentions. No Nays. The Motion Carries.