



**Meeting Minutes
 Children’s Disability Advisory Committee
 Department of Health Care Policy and Financing**

Colorado Department of Public Health and Environment
 4300 Cherry Creek Drive South, C-1-A Room Located in building C
 Denver, CO 80246

*Note: Participants need to sign-in at the CDPHE front desk in Building A
 to receive a badge for access to Building C.*

August 8, 2018
 10:00 a.m. to 12:00 p.m.
PHONE: 720-279-0026
PIN: 308112

Introductions

In the Room		On the Phone/Webinar	
Person	Agency	Person	Agency
Christy Blakely	Parent Advocate	Patricia Fulton	Arc of JeffCo
Beth Cole	Early Intervention Colorado	Danielle Schroeder	Colorado Access
Lindsay Westlund	HCPF	Stephanie Kimmen	Consultants for Children
Nina Snyder	HCPF	Nancy Harris	HCPF
Bethany Pray	CCLP	Allison Harris	Tennyson Center
Chris Russell	PPHC	Gina Robinson	HCPF
Carol Meredith	ARC	Erica Walczak	Jefferson County
Ryan Zeiger	PASCO	Tom Rose	Family Voices
		Kathleen Homan	HCPF
		Jocelyn Gilbert	Children’s Hospital



Agenda Items

1. Meeting Purpose

The purposes of this meeting is to share current issues in children's services. Christy Blakely reminded people to put their phones on mute. The webinar address is <https://cohcpf.adobe.connect.com/rx941divzcei> for people on the phone.

This group is a productive group that focuses on all children with special needs.

2. Introductions

3. New Business

a. Department Updates: Lindsay Westlund

Lindsay Westlund offered to start with the Children's Extensive Services (CES) waivers. The Department did post a new spending limit effective July 1, 2018. The 1% increase bumps up the limit to more than \$38,000. This is updated on the Department rates sheets, and a memo went out to all the case management agencies (CMAs.)

The update for the parental fees includes the stakeholder groups are still to be announced for August and September. Everyone who would like to be involved, please sign up for emails. Email hcbswaivers@state.co.us to sign up for the distribution list.

Ryan Zeiger asked if there was a targeted implementation date for parental fees. Lindsay Westlund answered that she's not aware of a date. The Department is still in the development phase. Ryan Zeiger asked if there was a piece of legislation, or if it was a line item in the budget. Bethany Pray clarified that it was a line item in the budget.

Lindsay Westlund continued that the Children's Habilitation Residential Program (CHRP) collaborative groups will be meeting as well. They will be going through the benefit collaborative processes for CHRP.

Carol Meredith said there is a date. The date is August 24th at 2:30 p.m. at the Department. Christy Blakely said people need to speak to Kimberly Smith at the Department about attending. Lindsay Westlund thanked Carol Meredith for that information.

Lindsay Westlund shared there was a delay bill passed regarding Electronic Visit Verification (EVV.) The bill delayed the penalty for reduced matching funds a year until January 1, 2020. Lindsay also told the group that they can sign up for EVV mails.



For the Children's Extensive Services (CES) waivers, Developmental Disabilities (DD) waiver, and the Supported Living Services (SLS) waiver renewals, there are upcoming stakeholder meetings. Dates and locations are still forthcoming. No questions from the phones or chat.

Stephanie Kimmen asked via the webinar chat what the meeting topic on August 24th was about. Christy Blakely answered it's a collaborative meeting to redesign the CHRP waiver. Christy asked Nancy Harris if she wanted to describe the waiver, but Nancy said Christy should give the basics.

Christy Blakely explained the CHRP waiver is one of the Colorado state waivers, the Home and Community Based (HCBS) waivers. CHRP was a program that supported children in out-of-home placement that were being habilitated in some way. They kind of crossed over into foster care, it's not a typical HCBS waiver. It's been worked through the counties previously, but now that waiver has come to HCPF. Nancy Harris moved from the Colorado Department of Human Services (CDHS) to HCPF to oversee the waiver. There are elements of the waiver to be redesigned.

b. Applying for HCBS Waivers: Christy Blakely

Christy Blakely shared another item to talk about, which is applying for HCBS waivers. Some families think it's not worth the effort. Christy Blakely said the group should discuss barriers that families encounter.

Christy Blakely said she would start the conversation with what people are hearing from families who just moved here, or are otherwise getting on waiver for the first time. Carol Meredith shared that the state currently has four different waivers: Children's Extensive Services (CES,) Children with Life Limiting Illnesses (CLLI,) Children's Habilitation Residential Program (CHRP), Children's Home and Community-Based Services (CHCBS), and Children with Disability Buy In program.

Christy Blakely continued that the group could add on the Brain Injury (BI) waiver because that starts at age sixteen. As people identify problems, issues and barriers, make sure to identify which waiver. That will help track the problem. This group did create a document called "Choosing a Children's Waiver," which is a nice graphic and flowchart. However, it includes the Children with Autism (CWA) waiver, which does not exist any longer.

Ryan Zeiger said the document is a really good tool with someone who knows the system. Christy Russell said that parents would have to take it to a case manager.

Carol Meredith said she would like to start out with an overarching barrier. The other systems of care, i.e. the Regional Accountable Entities (RAEs), don't understand the children's waiver system at all. For example, they don't understand that the Community



Centered Boards (CCBs) only do the CES waivers. Carol Meredith said the group should explain how this works in all the systems of care.

Ryan Zeiger agreed that in the Single Entry Points (SEPs) and CCBS, there is a varied amount of knowledge about the other waivers. There is also a lot of case manager turn over.

Bethany Pray said an issue is how people access the waiver. She stated CM's at CCB's and SEP's have very little information [about the larger system of benefits]. The case manager is seeing a piece of the system and that means there isn't any case management. If a child has mental health and CES, there is no one that can completely manage those [both programs involved in care].

Christy Blakely said families get into the Medicaid house, but if the kids are under 21, families also get on the children's benefits. Case managers should say let's go over your needs, and which needs will be met by which system. That's what waivers were intended to do, to bridge the gap. There aren't case managers at this point who ask all those questions.

Bethany Pray also shared another wrinkle is when people need state plan services and waivers services [there's not a CM for both programs.] Christy Blakely interjected that the group is not beating case managers over the head. There's a huge amount of turnover.

Ryan Zeiger said that case management is all over the place with RAEs, SEPs, CCBs, schools and home health. For example, PASCO got outreach yesterday from someone who is at a Behavioral Health Organization (BHO) who asked if PASCO could explain it all. However, Arizona has an interesting model from a case management experience. Arizona has a statewide call center, so members can call and get all the information is at once.

Tiffany from Developmental Pathways asked if anyone has tried the No Wrong Door (NWD) phone number. Carol Meredith said she thought NWD was about accessing Long Term Services and Supports. Tiffany said it could have morphed into just long-term care. Jocelyn Gilbert from webinar said she has never heard of the NWD number, and she has been in this for past nine years. Lindsay Westlund offered to have someone from the department to come speak about the No Wrong Door initiative.

Bethany Pray circled back to the training issue, which is always a tough one. The Department is usually good at offering training but not mandating it. She clarified that she is talking about EPSDT training specifically, as she doesn't know about the waivers.

Jocelyn Gilbert shared that she helps parents through waiver process. She works with children with down syndrome primarily. Families don't understand the waivers, don't



understand the difference between CHCBS and Children's Buy-In. It's very confusing to go through the different waivers, and who you go to, i.e. try this one first, then try this one second. It's very subjective at times, whether or not the child is approved. Jocelyn said her child has a disability, but he didn't get on the waiver until he was seven. Jocelyn paid thousands and thousands of dollars in medical bills because she was told no by a SEP. Looking back, she can guarantee it was misinformation. They said his medical comorbidity would not meet medical criteria. Knowing what she knows now, he should have qualified.

Lindsay Westlund said she appreciates people sharing their experiences. The Department is trying to break down the silos. Lindsay said the Department is looking at benefits that serve someone with a need rather than a waiver. The Department is taking steps to fix this on our end. Hopefully, that will filter into other areas as well.

Lindsay continued that she is hearing the Department needs to offer more training on children's services in general, but not specific waivers. So even if a case manager is at a SEP, they know what services are available elsewhere.

Chris Russell said it used to be if clients qualified for the CHCBS waiver, clients needed a denial letter from SSI. Just before this meeting started, a mom told me that SSI wouldn't give her more info. The SSI piece is hanging out there as a rogue piece. It would be nice if there was some guidance on how to do SSI appropriately.

Chris Russell continued that the general Medicaid application has gone to 43 pages. People say they don't have time to do that. They don't want to do that, even though it's worth the time it takes. However, 43 pages is ridiculous. That's on top of the disability determination paperwork.

Christy Blakely asked if people have to do the paperwork every year. Chris Russell said people should do it every year, just in case parent's income and assets change. Christy Blakely suggested there could be some way to streamline the application. Right now, families are bouncing around like a ping-pong ball.

Bethany Pray asked why parents have to provide that information, if the waiver is on behalf of a child. Chris Russell said there's no purpose for the financial information for the waiver. Chris directs people to say the application is being filled out as if the child was head of household.

Bethany Pray asks if the application includes citizen or non-citizen information. Christy Blakely said that yes, it does. She just went through that for her daughter, who is 36 years old. Christy and her daughter are not in the same household. The Department wanted all that information. Christy got a notice in the mail, and then she delivered it to the county.



Bethany Pray shared that federal regulations say that the Department shouldn't request information if it's not required for eligibility. It was stated that the Department has said it will not ask for citizen information from non-applicants.

Lindsay Westlund continued that there is a speaker scheduled to talk about eligibility for next month.

Erica Walczak shared what she's been told, which is only for families of children filling out the packet in Jefferson County. This is for minor children only. Just having the children's information, that has come into the financial department. What's happened is that the child has been coded as Modified Adjusted Gross Income-based Medical Assistance (MAGI) prior to a functional assessment. Everything gets sent out -- the card, etc. -- but Erica hasn't done the assessment yet. Families are using Medicaid because their income has been zero. The financial department codes the income as zero, or they get denied functionally.

Chris Russell asked if Jefferson County could just hold the paperwork. Erica Walczak answered that the people on the financial side don't know it's a children's waiver [application]. There's no box for CHCBS, for example. Erica added one more thing, when the rollout happens for the parental fee, they need to get household income and size to determine the fee. That's another reason to have household income on there.

Christy Blakely said the meeting is getting somewhere, with some barriers and what to chew on for next time. Christy moved to close this part and move on to provider capacity.

c. Provider Capacity: Christy Blakely, Lindsay Westlund

Christy Blakely shared that there is a capacity issue with staffing. There is also a capacity issue with accessing the services. Capacity also came up with conflict-free case management, and the access to Developmental Disabilities (DD) waiver services. Lindsay Westlund captured concerns on an "action planning" document through the webinar.

Ryan Zeiger said the group talked about the infrequency of respite at the last meeting. Sometimes we send out a registered nurse (RN) every two months to train providers in DD respite. This is for respite, even if the respite provider is going out once or twice a month. Ryan can't argue against training, but it's a barrier for low-frequency service. It makes more sense for high-frequency service.

Ryan reports PASCO has taken a conservative approach [to training], so PASCO trains on everything, including transfers.



Carol Meredith said they had a long discussion on the same topic yesterday at the executive directors of the ARC meeting. Carol said training a direct service provider (DSP) on transfers before they work for her son doesn't make sense. Her son is autistic so she needs to spend more time on behavioral issues, not transfers.

Ryan Zeiger agreed that provider don't want to lock up the DSP with a lot of training. Now that PASCO does behavioral therapy, behaviors is one area that always needs individualized training. Ryan added that there is traditional respite paid as respite. And then there's other services people use in lieu of respite.

Carol Meredith shared that direct service providers (DSPs) who already CNA-licensed, the nurse oversight over licensure is exempt, unless it's out of scope of practice. Christy Blakely said that consistent respite time is essential, so individuals providing services and families can count on it.

Chris Russell said the chart is intended to cover respite in total, not only respite available through waivers. Chris suggested titling the document roads to respite. Chris suggested another column to specify which type of respite.

Bethany Pray offered that if different agencies that might be responsible, she would like more consistency in licensing. Chris Russell said if parent hire a babysitter, there's no agency oversight. If parents receive services from a respite provider, Chris asked if there is something a parent signs off on in terms of liability.

Ryan Zeiger shared the concept of licensure from the state's perspective. If providers follow rules under Medicaid funding, and deliver same service under private pay, providers follow the same rules. For licensed agencies, that's the approach they take.

Lindsay Westlund said the "action planning" document still needs work, and suggests the group continues it at the next meeting. Ryan Zeiger offered to share some ideas with Lindsay after the meeting. Lindsay agreed to that idea.

d. Kaiser Permanente: Beth Cole

Beth Cole asked to add an agenda item to the meeting. Beth heard two different scenarios of kids who are on Medicaid who have a primary care physician (PCP) through Kaiser Permanente. The issue is that one of the occupational therapists (OT) is having money taken back because she should be billing Medicaid.

Another issue is that an Urgent Care said the facility can't see a patient because he has Kaiser. The PCP is Kaiser, but the individual has fee-for-service Medicaid. Beth Cole asked how the Department informs providers like the OT or Urgent Care on how to bill Medicaid correctly.



Ryan Zeiger shared that Kaiser gets some sort of payment, it's not fee for service, it's capitated. Kaiser's whole model is members work in our system. When they bring on Medicaid recipients, they take some approach. Once you enroll with Kaiser, members are supposed to use their network.

Gina Robinson shared that Kaiser is fee for service right now. Gina said that the Department did have an Urgent Care issue where they billed the patient. At first, they billed Kaiser but didn't bill Medicaid. It really comes down to the provider front desk staff. Urgent Care centers have high turnover. The Department has put information in the provider bulletin, and the Department has shared communications.

Carol Meredith also said she has seen this issue once with an adult who was dually-insured with Cigna. The Urgent Care did not know how to bill. The family had to take the letter to the Urgent Care center. The mother was tenacious, and she was able to get the money back.

Carol Meredith suggested that a solution is to educate the families that families don't have to pay.

Ryan Zeiger asked if there is a distinct Medicaid code for Urgent Care. Gina Robinson answered if there's an Urgent Care that's attached to a hospital, they bill under the hospital. If it's a stand-alone, they bill under the stand-alone. Beth Cole chimed in that stand-alone ERs are also a problem.

Chris Russell asked if provider portal is going to be available to families. It seems like it dropped off the radar. Gina Robinson answered no, it got moved so far down the list, it's moved way down in the system. Gina said she and Lindsay Westlund can try to figure out where that is.

Bethany Pray said there is information available on PEAK. Chris Russell said a lot of people who are referred to her really don't have a clue on how they are accessing Medicaid. The problem is with this new system, it changes lightning fast.

Gina Robinson asked why does it matter to parents how they got Medicaid. For 80% of the population, it doesn't matter to them.

Carol Meredith said families are frankly confused. And so is she, despite the fact that she's been doing this for 30 years. Carol said the Department has got to simplify this, at least with families. The families can't sit here every day at these meetings.

Gina Robinson said the Department pays three separate agencies for case management. The case management agencies should be doing that.



Christy Blakely asked if Gina was on the phone when the meeting was discussing RAEs and what they're getting as training. Gina Robinson said she heard the issue. Beth Cole agreed that it's a problem and we need more education with the sources and the families.

Gina Robinson clarified that if families need those letters [a cease billing a Medicaid client for services letter], they can call the client services contact.

Chris Russell asked if the Department can pull a list of Colorado medical providers with addresses from the NPI registry. Gina Robinson said she doesn't don't know if the Department can do that if Medicaid is not contracted with them.

Bethany Pray mentioned that two years ago, there was a bill to allow non-Medicaid physicians to charge Medicaid enrollees. Carol Meredith shared that there was a huge discussion about this on the listserv. There are parents who want to pay a non-Medicaid provider because they want to have that quality of care.

Gina Robinson cautioned against that route. Several years ago, all the emergency room (ER) doctors refused to join Colorado Medicaid, and families got ER bills every time they walked into the ER.

Carol Meredith said everything gets back to the capacity issue. Families give up on finding a PCP and just go to the ER. That capacity side needs to be elevated.

Chris Russell asked if there a is a way that advocates might be able to access that letter [letter to providers to cease billing a Medicaid client] the Department sends out to Medicaid clients. Gina Robinson answered no, it's specific to each provider and member. Gina said she can share a sample letter with the information taken out.

Christy Blakely said folks who are running blogs and listservs should put the message up there to remind people that if members have Medicaid, they can't be billed. Christy Blakely said the meeting is moving in the right direction. Christy reminded attendees that she will bring cinnamon rolls next month.

Lindsay Westlund shared that next month, speakers will discuss transitional Medicaid and conflict-free case management. Carol Meredith requested someone to talk about the issue of when families are applying for Medicaid for a child under 18. Carol would like someone to speak about if families have to include their income in the waiver.

Gina Robinson shared that Kathryn Ciano-McGee has gone around and around with Colorado Access. They want to be able to run all the eligibility for all people down to the waiver level. Gina suggested it might be worth it for people from Colorado Access SEP to come out and speak.



4. Old Business

a. Pediatric Behavioral Therapies Update: Gina Robinson

Gina Robinson shared that there was a 33-member drop in clients this month from May to June, mainly because of summer. She had several providers who requested that she send out emails for immediate openings. The Department had more unique providers, with an increase from 69 to 75 providers. The Department had 558 PARs completed.

Gina shared one of the new questions the Department is asking: Does this child have a diagnosis that shows a behavioral therapy will help them? Around 20 answered no, but the Department approved the PARs anyway.

Gina Robinson said she is not sure if the question is worded correctly. Others are answering yes all the time, and others are answering no all the time. The Department is not getting good, valuable information from that question.

Ryan Zeiger said PASCO has a significant number of people on a list for assessments. PASCO doesn't call it a waiting list -- instead it's called it a tickler list. He wondered at the reason why there are still people on the tickler list. There seems to be a good expansion of provider capacity.

Gina Robinson shared that families may want those wonder hours between 5 p.m. and 8 p.m. However, there are no providers available at this time. A lot of them wait for PASCO because they want one company to provide personal care and Early Periodic Screening, Diagnosis and Treatment (EPSDT.)

Bethany Pray asked what the specific diagnosis was for the people saying that behavioral therapies won't benefit the child. Gina Robinson said she didn't know, but there are diagnoses that are not normally typically known for benefitting from behavioral therapy.

Ryan Zeiger shared that PASCO saw that the agency was taking too long when taking people through the assessment. PASCO was being too thorough, but now PASCO tries to move more people into services. PASCO might have been going overboard up front.

b. Private Duty Nursing: Christy Blakely

Christy Blakely shared that she had no updates on the topic. She suggested moving onto future topics in the interests of time.



5. Future Meeting Topics: Lindsay Westlund

Kathleen Homan offered the statute (CRS 25.5.4-301) that said it's illegal to bill Medicaid members.

Lindsay Westlund said the list of topics for next month's meeting include:

- Eligibility
- No Wrong Door
- Conflict-free case management

Ryan Zeiger asked if there would be time to continue the work on the action planning chart. Christy Blakely replied that there is a full agenda for next month, so there might not be time next month.

Chris Russell gave Lindsay Westlund the phone number for Colorado Access. Kathleen Homan offered to have an off-line meeting for respite. Kathleen is working on the HCBS benefit for respite. Several people wanted to participate.

Bethany Pray requested a discussion about how the meeting can have a more diverse set of points of view for the committee. Bethany suggested working on outreach, or travel reimbursement so people can get here. Bethany also suggested not holding meetings during work hours.

Christy Blakely said the webinar is a step in a right direction. She asked if there was anyone specific Bethany Pray wanted to reach out to for the meeting. Bethany Pray answered families with disabilities. Chris Russell suggested people who disseminate information, so they in turn give 50 people the information.

Lisa offered to invite Chrissy Carrera, who coordinates the Padre a Padre meeting, which is the Spanish-language Parent to Parent meeting. Chrissy Carrera works closely with the Spanish-speaking clients. Lisa can invite them to attend this meeting.

6. Adjourn

Christy Blakely moved to adjourn the meeting.

Reasonable accommodations will be provided upon request for persons with disabilities. Please notify Lindsay Westlund at 303-866-5156 or lindsay.westlund@state.co.us or the 504/ADA Coordinator at hcpf504ada@state.co.us at least one week prior to the meeting to make arrangements.

