



MINUTES

Children's Disability Advisory Committee

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

May 13, 2020

10:00 a.m. to 12:00 p.m.

Phone: 720-279-0026 or 1-877-820-7831

Pin: 308112#

Webinar: <https://cohcpf.adobeconnect.com/childcommittee/>

Meeting Purpose

To share current issues in children's services - Christy Blakley

1. Introductions

2. New Business

- Pediatric Behavioral Therapies Questions Updates - Gina Robinson

Gave an update about the webinar for pediatric providers. When we talk about pediatric behavioral therapy, we allow several kinds of pediatric behavioral therapy not just ABA although it is the bulk of the services provided.

In relation to the new questions under the PAR process at eQ Sites, these were added for many reasons – the Children's Services Steering committee wondered why a PAR was approved when a provider says these services are not going to be what this child needs, then we wondered why the PAR was approved and what services this child was actually getting. In order to get better answers we have changed some of the questions around. We have also asked our UM vendor to hire some BCBA's as the first level of reviewing. They have a PhD as a second level reviewer and they have a board-certified Child and Adult Psychiatrist as the third level reviewer. We now have three tiers of reviews. Remember: We were told by CMS that we had very short time to get a benefit up and running. We tried to be open about the benefit from the beginning. Now we are trying to go back and learn from our

providers and other states. We have a number of great providers helping with these questions. Some of these questions that were changed are:
Does this therapy require 2:1 support? One of the things we were looking at is if kids need two providers. We know that these need to go for immediate review and it is helpful for EQ to know that. Some of the questions have been the same. One of these is regarding back billing and backdated prior authorizations. Those types of questions remain the same.
Are they in EI? if they are, we want to know it and make sure they are getting those services.

We asked questions about the waitlist. One thing we heard is that parents are having to wait a great deal of time between when they ask for services and when they get them. Now we ask how long a child has been on a waitlist prior to an assessment. We are having some language changes to see if we can get information from what each side wants to know. Is it a scheduling issue with the assessment or is it a scheduling issue on the parent's side? Hopefully this will give us an idea of where those issues are and see if we can help with that. It is just trying to gather information on what is going on with the benefit and the concerns we are hearing from parents.

Screening tool- we were allowing providers to write in what they were using as their screening tool. We had what looked to be over 7000 tools but when we really looked at the information it was closer to 5 they were just named different. We have included the top five with an additional "other" category so we can gather helpful information.

We removed school from one question because we cannot ask for the IEP since we are Medicaid. It is not that we aren't saying the child doesn't have behaviors at school.

Does the child present a safety risk to self or others? This wording was a concern for the Steering Committee because if they answer no it may appear the child does not qualify for services. We heard from review staff that these can take longer to review. It does not mean an automatic denial. None of these are automatically denied. Everyone is reviewed and looked at. We did hear from CMS we could not ask if the child's primary caregiver is able to support care plan. This was left in at the provider request. It has nothing to do with the PAR approval process; it is more about documentation for the provider ending services. ie a parent is not supporting the care plan the provider can then take the steps to end services.

Question: Can the IFSP we accepted as the assessment tool be the assessment tool.

Answer: The IFSP is not acceptable as an assessment tool, it can be provided as additional supporting documentation

Question: Did I hear EQ is not able to ask for an IEP for Pediatric PDN

Answer: I cannot answer for other benefits. We are only talking about Pediatric Behavioral Therapy and no, they cannot ask for it.

We have had very little feedback from parents or providers that these questions are causing any issues. The Children's Services Steering Committee will go in in October and look at the data. If we are still not getting useful data we will go back to that group of providers and the Steering Committee to make sure we are making changes everyone is okay with.

Question: Parents with divorced homes, are services limited to be provided in only one of those households?

Answer: No - the provider can split time between the two homes.

For reauthorizations every 12 mos. there should be an assessment. We did have some providers push back on that. They feel that if they are working with the child they should not have to do a reassessment of that. It is part of the national standard practice. The assessment has nothing to do with the child's diagnosis.

At the providers request we have also added a place to document discharge criteria so that if the provider does not think that the child is making progress or if the family is not complying with the plan they can provide that information in order to discharge. Basically they are saying yes, the child still needs services but I am not the one to be providing that.

Group therapy criteria- we want kiddos to be able to practice what they have learned and be in the community with less intensive services. The criteria was presented for that. That was also developed by the providers.

Next Steps- Common treatment form. Right now we offer so many kinds of therapy it can be hard for people reviewing the par requests. We want to work with EQ to create a common treatment form to cover all of the

modalities. Like a cover sheet to have who, what, when, where and why. We have 14 providers willing to help. We made sure to have one provider from each modality type. We will start those meetings end of June and we are hoping to have something out for reaction by end of year.

We want to work with UM vendor to flag suspicious behavior. We have heard clearly that maybe some of the care that is being provided isn't up to standard. Now having these reviews in place we can say some people saying they are providing ABA therapy are not meeting ABA standards. We are working with them on getting documentation up to standard or are giving the option of providing a different kind of therapy and ensuring they are meeting those therapy documentation requirements. We really want to be able to gather data on the screening tools to see if we need to mandate a screening tool. Right now we do not mandate a tool. We did hear from some providers that they want us to mandate a tool. We are going to look at the questions and see what the data says.

There are assistants in some modalities (BCaBA) who are able to practice. Right now we don't recognize them. When we asked a few months ago there were two and they didn't care to be recognized. We are hearing now there are hundreds and they want to be recognized and possibly have a pay rate for that level.

School language has been removed. If the parents feel strongly we can put it back in we would just need to let providers know they do not need to submit that documentation or lead them to believe that its required to submit the forms like the IFSP.

Not paying for parent education. Across the board Medicaid doesn't pay for parent education. We will continue those conversations.

Two providers have offered to hold webinars on best practices. We had our first group yesterday. They came up with their first agenda - how to ask for 2:1. How to talk about medical necessity. They are going to do a webinar for that as well.

Questions: How does one find out about those?

Answer: As soon as there is a date and time I will send out that information to the group.

- Check in with the Committee - Christy Blakely

How are we doing out there? A few short weeks left of school. Families are going to have one less thing to do after that. How are you holding up? I really want to hear what folks are experiencing. If there are barriers we need to be addressing.

Stakeholder: We have been working on getting information out to families about respite. How to go about getting respite safely and how that might look. Look for some marketing materials going out soon. I am worried about this long time when kids don't have school.

Stakeholder: We have heard families and providers are concerned about how to provide services in the homes again.

Response: I think wearing a mask and hand washing. I think using as many precautions as possible but I'm also hearing about school districts that are having families keep their technology. I am not seeing an end until we have more adequate testing and immunizations.

Question: Wondering whom to talk with if Medicaid clients are losing eligibility despite the COVID hold on loss of Medicaid.

Response: you can send an email to our COVID inbox at [HCPF HCBS Questions@state.co.us](mailto:HCPF_HCBS_Questions@state.co.us)

Response: We are not going to be decreasing benefits for anyone during the public emergency we have also built in some safeguards. If you are seeing a decrease in your benefits please reach out to your counties or us at the department and we can research this.

Most counties are in fact working but most are partial or full remote staff. We have a county matrix on our HCPF covid site to tell you which counties are open. You can also check your status on the PEAK website. Some of the notices may have been sent prior to updates in our system.

- COVID – 19 and Department Responses - Candace Bailey

www.colorado.gov/hcpf/long-term-services-and-supports-covid-19-response

This link is all things Long-Term Care for the Department. We have posted 46 operational memos thus far. There are a number of things around case

management about not doing in person visits or collecting signatures. There is a ton of information. This is also where our webinar information is posted. Please feel free to join the disability webinars on Fridays. You can get the link on that site. If you are a provider including case managers and PACE those are also on Friday.

If you have a question please send it to the inbox. We have several staff checking it daily. It can take a while to get responses. We trend questions coming into the inbox to inform our FAQs and webinars. There is no end in site for rolling back telehealth visits at this point. Those are the things we are working on right now.

Question: Is there a recording of the webinars

Response: Yes, they are recorded and posted. We will get more info on the social distancing webinar.

- Behavioral Health Subcommittee - John Laukkanen

My role is to connect HCPF with CDHS overlap where child services are involved. Part of my duties outside of formal connection and liaising role is serving on the Behavioral Health Task force with the goal to look at the system in CO and make recommendations for reform. There really isn't a system. It is more of a patchwork of entities to try to find resources in the state. The goal is to make that better and make some pretty bold recommendations. The idea is to make a taskforce big enough to represent stakeholders. There are three subcommittees including the Children's subcommittee. We were given a blank slate to look at it and come back with our best work. We have used the systems of care approach as a guiding outline. We have broken down 6 areas to look at. Tomorrow is our first look at the finance piece. We contracted a financial map. This coming meeting we will be presenting draft recommendations. Our work will end in July. Our recommendations in those six areas will be rolled in with the other subcommittees and handed to Polis to take action with the hope that there is some real reform in the state. One key component is listening sessions. There is a public testimony session for anyone connected to IDD community. There are other sessions hosted by different members of the subcommittee. We want everyone's voice to be heard as we create this blueprint.

Carol Meredith- One thing the committee agreed upon is that we go from birth to age 26 because we knew that behavioral issues for children bleed into the early transition years.

Stakeholder: Without committing to recommendations, can you share some of the themes that you have been hearing regarding children's services and needs?

Everything from how siloed, ineffective, expensive the system is. We want quality metrics to measure if the new system is successful. We have some draft recommendations on how to measure the quality. That metric of functionality is part of the recommendations. Everything from that idea to how to ensure access and how to pay for it all. We are looking at the workforce. How do we build, expand, equip all of those things that go into building a workforce? Looking at how we address information sharing and consent.

Listening sessions are during the day but there is a way to write in something to be shared on your behalf.

We start some of our meetings listening to testimonies. Everybody has a unique story and we want to do as much as we can to build a system that people can use and access and provide quality services.

One of the last things we will do is a review and analysis of all of those testimonies. That analysis will be presented in our July meeting when we will have our recommendations in draft so we can make sure we are hitting the mark with whatever we do. We want to hear your voice.

www.colorado.gov/cdhs/colorado-behavioral-health-task-force

Public Testimony with IDD Community Tuesday, May 26 1:30 – 3:30pm Virtual Listening Session Description: This will be a virtual listening session only. Join Zoom Meeting: <https://zoom.us/j/9166858148> or 1-669-900-6833, Meeting ID: 916 685 8148; Password: 679034 Hosted by Cordelia Robinson Rosenberg and Patricia Oliver With Lt. Governor Dianne Primavera and Executive Director Michelle Barnes.

3. Old Business

- CLLI Physician's Life Limiting Illness Documentation Lindsay Westlund Waiver Renewal is with CMS being reviewed with effective date 7/1

Something brought up through stakeholder engagement was the Physician statement of life limiting illness. There are still some updates that need to be

made on this form. A lot of comments were made about doctors not wanting to fill out this form.

Some language to the doctor about the waiver itself and what is needed by the physician. Does a really nice job of a high level overview of the waiver and its intent. If you have any feedback about the language please feel free to send those comments to me.

It gets a little trickier further down. We have to be very careful about not expanding eligibility for this waiver. We have to be very careful to define things the same as we do in the waiver application. We probably won't be able to use the definition section but we can probably use parts of the form to really focus the physician on the department's definition of LLI so they are able to say yes or no. These are just recommended changes so I am still looking for feedback but just wanted to present some of the feedback I have gotten so far.

I definitely welcome a physician's feedback as well. Feedback can be emailed to Lindsay.Westlund@state.co.us

Stakeholder comment: That definition seems to be pretty limited. The primary group that it overlooks with that definition is cancer diagnosis because they can be excluded because of a reasonable prognosis but could benefit from these services. I know that is not something that we would be able to change but California uses Life Threatening which is a little more inclusive and aligns with the palliative care.

Stakeholder comment: This waiver has historically been for palliative care and what it encompasses and that is the hope with this. Some physicians when they are not comfortable with this terminology could exclude families. The WHO definition starts palliative care from the day of diagnosis.

Response: I understand that the WHO definition is much more inclusive but at this point in time it is not something we can do due to financial impact. As you know the state is in a budget shortfall so expanding the eligibility definition is just not an option at this point.

Stakeholder comment: My understanding while making these recommendations is that we target kiddos that qualify for the program but that physician's don't understand the waiver and language.

Stakeholder Comment: My understanding was that this program was for children who may have a cancer diagnosis but a positive prognosis but have been experiencing the trauma of cancer and could benefit from those services.

Response: This waiver was designed as a hospice waiver. It has moved more towards palliative care but it is designed for children who will likely not make it to adulthood.

4. Public Comment

We are watching what the legislators are doing and making sure kids with disabilities will not experience service cuts. We will keep an eye on that.

Lisa Franklin, Parent to Parent of Colorado: I think a budget presentation in June specific to Medicaid for children with special needs would be very helpful!

5. Adjourn