



**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 in order to receive a badge for access to Building C.*

November 14, 2018  
 10:00 a.m. to 12:00 p.m.  
**PHONE: 720-279-0026**  
**PIN: 308112**

**Introductions**

<b>In the Room</b>		<b>On the Phone/Webinar</b>	
<b>Person</b>	<b>Agency</b>	<b>Person</b>	<b>Agency</b>
Christy Blakely	Parent Advocate	Ryan Zeiger	PASCO
Chris Russell		June	PASCO
Lindsay Westlund	HCPF	Matt Stone	PASCO
Nina Snyder	HCPF	Erica Swanson	PASCO
Michelle Craig	HCPF	Nancy Harris	HCPF
Heather Peters	Advocacy Denver	Erica Walczak	Jefferson County
Beth Cole		Jessica Bayer	Colorado Access
Bethany Pray	CCLP	Danielle Schroeder	Colorado Access
Heather Peters	Advocacy Denver	Carol Meredith	ARC
Stephanie Kimmen	Consultants for Children	Ann McNally	RMHS
Heidi Heins		Jocelyn Gilbert	Children’s Hospital
Jyoti Sapkota	DHHA	Kathleen Homan	HCPF
Justine Miracle	HCPF		



## Agenda Items

### 1. Meeting Purpose: Christy Blakely

Christy Blakely shared that the purpose of this meeting is to share current issues in children's services. The attendees want to find the barriers that children face in the system and resolve the problems. The meeting attendees are trying to educate themselves and move ahead with good ideas.

### 2. New Business

#### a. CHRP Redesign: Michelle Craig, Nancy Harris

Michelle Craig introduced herself as a supervisor for the Complex Needs Program Development and Evaluation Unit, which focuses on complex supports for members. One of these projects is the Children's Residential Health Program (CHRP) waiver renewal. Nancy Harris continues to be the CHRP waiver administrator. Michelle noted that there are a number of people in the room who have participated in the benefits collaborative. However, the Department wants to make sure it's reaching out to as many stakeholders as possible. Some of the information may be redundant.

Michelle Craig explained that the CHRP expansion nicely aligns with the Office of Community Living mission, which works toward person-centered support.

Michelle Craig shared that the Department is working to remove requirement that CHRP children be in foster care. CHRP is being moved from the Colorado Department of Human Services (CDHS) to the Department. Nancy Harris now works for the Department effective July 1, 2018. Children served through foster care can still access CHRP, but it's not going to be a requirement. The Department is working on transferring management of cases from child welfare to case management agencies. The Department is also adding two new services to allow children to remain in family home or transition back into family home.

Michelle Craig displayed a slide outlining CHRP's future. CHRP will still serve child welfare system children experiencing abuse or neglect, but it will expand services. The first step is engaging stakeholders on new benefits from August 2018 through January 2019. The next step is to renew the waiver with CMS from February – June 2019. The third step is to promulgate rules and regulations from February – June 2019 as well. Then we will train on expanded CHRP waiver from April – June 2019. The last step is to transition to expanded CHRP waiver in July 2019.

Michelle Craig clarified that the waiver period now is through June 2019, so the Department has to renew the waiver anyway. Justine Miracle is working on the waiver



renewal, in step with Candace Bailey and Lindsay Westlund. Training also includes education because the Department wants to communicate changes to a broad audience. The Department is offering training to hospitals, Community-Centered Boards (CCBs) and providers. The Department also wants to educate families on the new benefits.

Michelle Craig emphasized that changes made aren't going to result in any changes for current CHRP waiver clients. There are currently about 40 children on the waiver. The Department can work with each county and CCB to identify individual case management plans for each child on the waiver. For the benefits collaborative, the Department was open to feedback. The Department had a rough framework but received a lot of great feedback. Now the Department is in the process of finalizing final drafts. The third meeting will be held on November 30, 2018.

The slide presentation is available to download. Lindsay Westlund offered to send out the link to the group.

Michelle Craig asked attendees to look at links in presentation for more information, or to sign up for the collaborative. Email Michelle or Kimberly Smith to sign up for the third meeting. The time is 3:00 - 4:30 p.m. in room 7ABC, November 30, 2018.

Justine Miracle introduced herself as the development specialist for the CHRP waiver. She will be working on developing the new services, and all the things that go into developing new services. Feel free to email Justine as well.

Michelle Craig reminded people that they can join the webinar or send in comments if unable to attend the meeting in person. Michelle said the Department is on a very fast timeline, which is unusual for the Department, but things are on track and going well.

Christy Blakely said she is excited about the CHRP redesign. When she has creative solutions calls, she can get twenty people on the call. Christy shared that she often has less than a day because the kid is in crisis. If the kid goes home with no support, there will be another event, and sometimes people get hurt. Then it starts all over again. If parents can use this resource, chances are the family will have a better transition, but it's also going to help the child. Low cognition and behavioral needs is a tough diagnosis, and there are not a lot of folks who manage that population. Case managers often send them out of state, which is a high cost.

Michelle Craig said the transition service is designed for just that scenario, for children in out-of-home placement. But she could change that language to hospitalization or out-of-state. The service will be allowed to start days before discharge, or even immediately upon admission to start planning.



Christy Blakely acknowledged that's a good point. She has talked about services as a relay race. It's crazy because we need that continuity with those kids. With Intellectual and Developmental Disabilities (IDD,) people often think a week, and the kid's fixed. That works with a broken bone but not with mental health. If people think nothing's going to trigger those kids, people are dreaming.

Michelle Craig continued that the Department is doing all of this in the larger frame of the renewal of the CHRP waiver. The waiver has not been amended in five years, so there's a variety of things that need to be updated. The stakeholder engagement meeting on the HCBS-CHRP Waiver meeting is Friday, December 7, 2018 from 9 a.m. – 12 noon at HCPF at 7B. The Department plans to send the informational memo out later this afternoon.

Michelle Craig finished up her presentation, pointing out the last slide is the distribution list for the HCBS-CHRP waiver. Send email to [hcbstwaivers@state.co.us](mailto:hcbstwaivers@state.co.us) to sign up for the distribution list. Future communications will be posted on website on OCL stakeholder site. There's nothing posted yet, but the Department will start posting it there when we have the informational memo.

Chris Russell asked if Michelle knows how many children are out of state. Michelle Craig answered, no, she doesn't.

Parent Brigitta Hebden asked a question about outreach planned for families. Michelle Craig answered the Department is working with CCBs, counties and providers. The Department is also working with CDHS, including child welfare and the Office of Behavioral Health (OBH.) If there are groups of people the Department should reach out to, please send the Department that information. The Department had some good input at the benefits collaborative meeting, but due to the nature of kids served in CHRP being in child welfare, the Department is not getting a lot of input from families.

Christy Blakely said there are many reasons why families are too busy to give input. Unfortunately, most of these families are isolated because they're dealing with the day-to-day. Many of them adopted these children, and they're supporting them in ways that boggle the mind, especially with court dates and the legal side. Reaching out to them is hard because they're often managing their one kid and trying to stay afloat. And they're normally not plugged in, plus the families are the ones that have to know. Until the families are in a crisis, case managers don't know. That's why the Arcs are so important.

Carol Meredith said that she knows that the benefits collaborative has been listed on the parent listserv. Reaching out to case managers, she thinks they might know families that are struggling with that level of support. What she has been hearing from wrap-around facilitators, a lot of case manager don't even go after the Children's Extensive



Support (CES) waiver, especially for people outside of the metro area. The case manager is just putting out fires all day. Case managers under CES waiver or mental health centers might be a good place to look.

Brigitta Hebden also recommended the Department contact pediatricians. Christy Blakely said that's a brilliant idea, getting with the pediatricians.

Michelle Craig said feedback on this is helpful. One of the things that the Department is going to do is try to have brochures at hospitals or pediatrician offices. If people have other ideas, the Department wants to get it far and wide because of the well-made point about families having a lot of stuff going on. Ultimately, the Department wants to make it easy on the families, whether if they're at the hospital or the pediatrician's office.

Justine Miracle said the Department has been partnering with the Regional Accountable Entities (RAEs) as well. Some of the RAEs are excited for this. Historically, physical and mental health have been siloed, including IDD. A few of the strongholds are wanting to break down the silos.

Bethany Pray asked if the Department is in contact with the adoptive parents of Colorado group. They're a good resource. Chris Russell also suggested the reactive attachment disorder (RAD) group. For example, kids with fetal alcohol syndrome. The Department needs to reach out to these folks.

Michelle Craig answered Brigitta's question about qualifications. The case manager will complete the 100.2 as they do for all the waivers. There has to be financial need as well. The other criterion is that the child have extraordinary support needs that could require out of home placement.

Michelle Craig continued that the CHRP does use an assessment tool called Inventory for Client and Agency Planning (ICAP.) That's an additional assessment that has been used in CHRP for quite some time because it's the financial piece. The Department is going to continue to use that for now. Eventually, the Department will be moving to another assessment tool for all waivers, which will eventually replace the ICAP. There is no nighttime criteria and no separate application.

Chris Russell stated there will be a lot of overlap between CES and CHRP. She asked if clients will be able to transition back to CES if kids need the CHRP waiver.

Michelle Craig answered yes, they can go back and forth. Long term, the Department would like to consolidate the waivers.



Chris Russell predicted that clients are going to wait until the very last minute because they don't want to lose the CES. It can take up to 6 months to get on CES waiver, waiting list or not.

Christy Blakely clarified that the CES waiver requires a monthly activity. So if a child is placed out of home, they lose that month. The Children and Youth Mental Treatment Act (CYMTA) could interact with that. However, it can be hard to understand where all the money comes from.

Michelle Craig offered that the Department discuss some kind of visual to address that issue. The wrap-around is embedded in the system of care philosophy. It looks at funding streams, and it also gets the child and the family on a single care plan.

Bethany Pray pointed out that there has been talk about consolidating waivers since she started this job 4 ½ years ago. The Department has so much work to change waivers. It has limited usefulness if then the Department is going to move to the next step of consolidating waivers. It's a lot of work for the Department and a lot of changes for families. She is wondering about the long-term vision for this.

Michelle Craig acknowledged the point is very well-made. Sometimes the incremental steps toward consolidating waivers feels very painful. With the CHRP, it is a first step. The Department can't do anything without legislative authority or federal authority. The Department is moving toward that, but it does expose gaps. This is phase one of CHRP work, we'll have time to evaluate after implementation.

Christy Blakely thanked Michelle Craig for her presentation.

#### **b. Spanish-Speaking: Christy Blakely**

Christy Blakey said she did meet with Brigitta about finding Spanish-speaking families to talk about difficulties with the CES waiver. Christy said she'll move the topic to later, but not next month because December is a difficult month for meetings.

### **3. Old Business**

#### **a. Children's Extensive Supports (CES) application review: Lindsay Westlund**

Lindsay Westlund shared said some of feedback from case management agencies about the CES waiver. Case managers are meeting with families up to three times to complete the CES application. She was not aware of that they were meeting with families that many times. The financial eligibility piece plays into that, the wait time for counties can be very long as well.



Chris Russell said that in her experience, when someone is sent to a Single-Entry Point (SEP) or one of the independent CMAs, it seems very organized. With the CES waiver, she feels like stuff is put on the family, and if the family doesn't do anything with it, nothing happens. The families are in crisis and they say the CCB doesn't get back to them. If the child was not a client before applying for the CES, they have to undergo the IQ test. If the school is not going to cooperate, it's a huge stumbling block. In a lot of cases, it's getting passed off to the Arcs to figure that out. The Arcs are unhappy that the IQ piece is passed off to them. The problem is people are languishing because they don't have that test done.

Chris Russell continued in the case of her clients, she begs and pleads with the Applied Behavior Analysis (ABA) division, to perform tests so they can move forward. If something is handed off to the family, it never happens. That's not just the CES waiver. She tries to push her clients along, but she doesn't see why it has to be that much harder than the other waivers.

Christy Blakely said the group should identify the barriers:

- Getting IQ testing and adaptive behavior testing.
- Support through the process for family.
- County backlog and getting financial stuff.

Chris Russell shared that one other barrier is that eQHealth requires that professionals back the families up with the claims, and that process that takes a long time.

Carol Meredith agreed that's a huge barrier. The case managers have to pull together hospital and school records. The family has to have someone with letters after their name to verify behaviors. Families are pulling together behavior plans, letters from doctors, and letters from respite providers. It's ridiculous.

Lindsay Westlund shared that is something the case managers brought up, that they're not supposed to submit that until they receive that documentation. They don't send the application until they have letters from doctors to eQHealth.

Chris Russell also shared that the families don't always have ABA providers to write letters, if they don't have the money for a therapist. There's a perception that nobody believes the families. Christy Blakely agreed that she has heard that more times than she count.

Ann Hanlon said she would like to weigh in on this because she has done tons of those applications. The supporting documentation unfortunately is in rule, it's a struggle for everybody. Especially kids that don't have a therapy team behind them. This is where Rocky Mountain Human Services have to get creative. RMHS had folk that were not



professionals, but who were people in that child's life. Someone that sees your kid regularly, the teacher or postman, someone who sees that kid often enough. This is open to interpretation from case management agencies. eQHealth is also requiring case managers lately to submit things they've never had to submit before.

Ann Hanlon continued what really slows down the process for her is the Medicaid application, also known as the financial eligibility. If the child has SSI, it's a little bizarre. Each county does long-term care waiver Medicaid differently. When the interChange went online, DHS didn't know what case managers were talking about when we said the Bridge. That has slowed down for her the entire determination process.

Ann Hanlon agreed that the issue that Chris brought up about the IQ scores is tricky. When RMHS has a kid who is eligible, but the agency cannot get professionals to give the testing that Colorado requires, she's begged teachers to do adaptive behavior testing. She realizes that families are overwhelmed. Families don't always remember who she is as the case manager. There are so many moving parts to this. Some of the ways we've gotten slowed down is at the county level. Ann said she pesters the counties.

Bethany Pray said sounds like there are so many different issues here. She's just going to talk about the supporting documentation. She's talking about how many hoops parents have to jump through. eQHealth is not making the state do anything, eQHealth is a vendor that does what the state requires them to do. If case managers know a kid is eligible, there should be a process that allows a kid to get on a waiver without a 8-month process. Is there anything the Department can do, working with eQHealth, that can make this process less complicated?

A case manager said she used to work with Denver Public Schools (DPS,) and she fought with them all the time to try to get testing. That's helping access to education, and it's really helping this child. She is just trying to be creative and think. She's worked for DPS, and she knows a lot of the players, so she can get some of it done. She no longer works for Denver Public Schools. She now works for Advocacy Denver.

Justine Miracle asked if school districts are required to do early intervention. Maybe that can be expanded. Chris Russell answered that there's a timeframe for when the IQ test needs to be done. If children have an IQ test at 4 years old, it doesn't count at 11 years old. However, the adaptive scales test is really simple. Chris wondered if it could be part of the intake for the CCB.

Ann Hanlon said there's a conflict between performing testing and finding people eligible. Ann agrees that Chris right about the adaptive being a very quick test. When there changes to the Children with Autism (CWA) waiver in 2000, the committee investigated if that test could be required.



Beth Cole said that one thing is that she keeps hearing is school, school, school. She suggested the meeting needs some school representation on this committee. Chris Russell said it all comes down to money. If they think it all comes down to IEP, it doesn't affect schools. With all the complex documentation, this little test seems like a big problem.

Bethany Pray asked for suggestions to make this process easier. She suggested other ways for the state to work with eQHealth to identify what corroborating evidence you need to show that parents are up every three hours, for example. She said it should not be a guessing game of what's going to be sufficient. The state just needs to make this clear. There's so many different scenarios, such as people who co-sleep, or people who have kids who are up all night for one week, but then the kids sleep for three weeks. Some clarity between the state and eQHealth would help.

Lindsay Westlund said she appreciates the dialogue, and the number of issues brought up for the CES waiver. Some of the steps that the Department takes to correct things seem little and painful. The Department has tried to implement ways to move forward. She has heard very loudly that the Department needs to work on relationship with eQHealth. The Department needs to work on what the vendor needs to review.

Lindsay Westlund continued that the Department has to follow the regulatory process for updating rules. For CES, we have to update waiver language, such as removing vision services. Cleaning up the waiver can be a slow-moving process. The Department will probably will have to work with stakeholder groups, that's a collaborative process as well. How the Department quantify behaviors, some folks have said it's arbitrary, and it differs so much from kid to kid. The Department also wants to look at targeting criteria. The Department can't make huge changes to targeting criteria without affecting our budget. The Department wants to approach it with this group. Lindsay would like to bring back a timeline and see what it actually looks like. Everyone can see a visual of the Department's goals to see a clear-cut pathway.

Christy Blakely joked that the Department could truncate the process by leaving the person who has to make the decision on the child in the house for a night.

Carol Meredith said she is done with the counties because case managers should not have to dog the counties through the system. She hears this from multiple entities. Redeterminations are not going well either, for people who are already on the waiver. Providers are not getting paid. She asked how this problem can become a higher priority issue for the counties.

Justine Miracle answered that she can't speak to that, but she appreciates Carol's perspective. It looks like how children function in multiple systems, such as schools and



home. It can be gamed, it's an algorithm. The CANS gets a lot of great feedback from around the country. The Department is going to evaluate CANS for the waivers. Maybe one day in the near future.

Lindsay Westlund said the call that she did do with case managers was how hard it would be for CES applications to include 100.2 information. It would take away that extra application, but it would require training for case managers. Based on that call, she feels like the agencies gave the go-ahead. If the Department can't eliminate the CES application altogether, the Department can pare it down to one or two pages.

Christy Blakely said she agreed with Carol that they shouldn't have to dog counties for paperwork. They do have an organization, Colorado Counties, Inc. (CCI.) She called the county commissioner, and it was fixed within 24 hours. Gina Robinson told me to do that. She took Lauren, her own child, to the county and just sat there. It was crazy.

Chris Blakely shared that calling the call center could take three hours. She's had kids lose their Medicaid who were on a waiver, and it was because the case manager from the SEP had submitted the paperwork to the county. But the county hadn't sent it in on time. The unbelievable chaos to get that fixed. Numerous cases because the county didn't get paperwork in on time

Lindsay Westlund offered to ask county liaisons from the Department about coming in to speak to this group. Christy Blakely said to warn them that we have a lot of passion. They don't always want to come to meetings like this. Bethany Pray thanked Lindsay Westlund for the timeline suggestion, that's very helpful.

Chris Russell also shared that she has had families that home modifications should be completed before getting kids kicked off waiver.

Ann Hanlon said the families can appeal. During appeal, they can't stop providing services. I would always suggest that families appeal right away.

Christy Blakely said Gina Robinson was up next, but she doesn't appear to be on the phone. Therefore, the update on Pediatric Behavioral Therapies will be moved to next month's meeting.

#### **b. Other Meetings: Lindsay Westlund**

Beth Cole announced that Saturday, November 17 from 11 am to 2:30 p.m., a nonprofit is having a World Prematurity Day Fundraiser. The primary speaker is Dr. Mom at Maggiano's little Italy in Englewood. Cost is \$35 and includes \$10 gift certificate to Maggiano's. Christy Blakely said Dr. Mom is a hoot and recommended people go hear her speak.



#### 4. Future Meeting Topics: Christy Blakely

Lindsay Westlund said she plans to continue setting meetings up here at the Colorado Department of Public Health (CDPHE) for next year.

Beth Cole said she would like to invite Alex Weichselbaum from the Department to the meeting in December. A notification recently went out that speech therapists will have to create PARs for families. There's still a lot of questions about it. What's happening with kids who are already seeing speech therapists, for example. Once kids are over three years old, it might discourage speech therapists from seeing kids. Lindsay Westlund said she will see if he's available in December.

Christy Blakely said she's heard those concerns from a mom as well. Medicaid in school funding hasn't looked at other funding, and now with PAR requirement, it will look at other funding. For example, a child has half-day kindergarten with speech therapy, then the kid goes to other therapy. They may be different goals, but now they will both be looked at with PAR. There's concerns on multiple levels.

Chris Russell said this would be something that would also be an eQHealth type of question. If speech therapy involves feeding therapy, there's some lack of coordination about what's duplicative. They're not clear at eQHealth what duplicative means.

Brigitta Hebden asked if they could put Spanish-speaking stakeholders on the meeting for January. Christy Blakely agreed that they can put that together by January. The meeting will also start the legislative update in January.

Lindsay Westlund said it sounds like the group wants to do a December meeting. Christy Blakely said it would be December 12. Ryan Zeiger seconded the motion. Beth Cole agreed that a lot of things are time sensitive.

Christy Blakely offered to bring treats because it's December. Brigitta and she will work on non-English speakers for January. She can't even imagine the issues with people who don't speak English.

Lindsay Westlund reiterated that she will ask the county liaisons and Alex Weichselbaum from the Department if they are available for the December meeting. Christy Blakely suggested that they leave a little space for future planning.

Christy Blakely mentioned one of the things that's bubbling up is the parental fee. Families are spending way more today on insurance on other things. Lindsay Westlund suggested asking Dennis for December instead of January.



## 5. Adjourn

Christy Blakely moved to adjourn the meeting 20 minutes early. Beth Cole wished everyone a Happy Thanksgiving.

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](mailto:lindsay.westlund@state.co.us) or the 504/ADA Coordinator at [hcpf504ada@state.co.us](mailto:hcpf504ada@state.co.us) at least one week prior to the meeting to make arrangements.

