



**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.*

June 13, 2018
 10:00 a.m. to 12:00 p.m.
PHONE: 720-279-0026
PIN: 308112

Introductions

In the Room		On the Phone	
Person	Agency	Person	Agency
Christy Blakely	Parent Advocate	Kathleen Homan	HCPF
Candace Bailey	HCPF	Gina Robinson	HCPF
Lindsay Westlund	HCPF	Tiffani Domokos	Developmental Pathways
Nina Snyder	HCPF	Brigitta Henson	Parent Advocate
Beth Cole	Early Intervention Colorado	Tom Rose	Family Voices
Chris Russell	PPHC	Ann McNally	RMHS
Carol Meredith	ARC	Erica Wolcott	JeffCo
Jyoti Sapkota	DHHA	Nancy Harris	CDHS
Bethany Pray	CCLP	Cynthia Chapman	Case manager
Heidi Heins	ARC	Ileana	Children’s Hospital
Brianne Carruthers	Student	Adam Steinbrunner	PASCO
		Allison Harris	Tennyson Center
		Catherine Dickerson	NMCS



Agenda Items

1. New Business

a. Department Staffing Update: Candace Bailey

Candace Bailey shared that Sheila Peil retired at the end of May. Sheila was a tireless advocate for children for many years. Candace is covering some of Sheila's work until the position is filled. Lindsay Westlund is also stepping up to help with Behavioral Therapy transitions, while Kathleen Homan is stepping in for respite. Candace will be attending the meeting until a new full-time staff person is assigned to the meeting.

Christy Blakely reminded attendees that this is a critical meeting for children. Christy said everyone should continue to work on the positive side of this.

b. Conflict-Free Case Management: Christy Blakely, Candace Bailey

Christy Blakely shared her concerns over the lack of service providers for the IDD waivers. Christy set up a Program Approved Service Agency (PASA) for her daughter, and she is getting up to six requests per day from two different Community Centered Boards (CCBs) for people who are needing services. Although the cut-off is two years from now, CCBs are starting to transition their service arm now. There are not enough service providers to meet the needs of the community. Many CCBs are really pushing to end their contracting.

Candace Bailey explained that the CCBs previously held contracts with a certain number of PASAs and individual providers. Since conflict-free case management, many have stopped the practice of contracting with individual providers and PASAs. The CCBs are referring people in a similar method to Single Entry Points (SEPs) now. For example, the CCBs have a list of agencies, and they refer people to a list of agencies.

Carol Meredith said CCBs used to do independent contracts with independent providers -- not necessarily PASAs, but independent contractors. The CCBs would pay the contractors a bulk rate for their service. Back in the day, providers didn't have to go through the PASA approval process. Five years ago, CCBs said this didn't meet the smell test for independent contractors because the contractors were told how to provide services, and how to do training. etc. This is directly related to labor laws.

Christy Blakely clarified that CCBs will no longer contract with individuals to provide services. A PASA is a whole different animal. PASAs are required to pay liability insurance, perform billing, and become a business in the state of Colorado. Christy said many PASAs are set up just for individual participants, and do not provide services to other participants. Christy also shared that the process was arduous, and she might not have completed it, except for the fact that her husband is a lawyer.



Candace Bailey said that the Department is responsible for ensuring that all provider agencies are a business. It has operated this way for many years because of the many different waivers. For example, the Children with Life-Limiting Illness (CLLI) waiver offers respite. SEPs refer out to an agency that provides respite, and then the agency provides the staff for respite. The agency may hire on parents or family members to provide respite. The agency hires the individuals. There are eleven waivers. You can find the waiver charts for children and adult waivers on the Department's website: www.colorado.gov/hcpf/long-term-services-and-supports-programs

Christy Blakely said all waivers come with services, but she is still concerned that there are not enough service providers. Christy suggested a small task group to watch the issue. Christy brought up another concern, which is that if families don't use the benefit from a waiver, they will lose the benefit. For example, if families don't use a Children's Extensive Support (CES) waiver service, they lose it after two months. Families can't find respite providers so they lose benefits from the waiver.

Candace Bailey offered to help spearhead an action plan. Some discussion followed on different qualifications for PASAs.

Christy Blakely said the group should keep this on the back burner. The task group can take this on and create a bullet list. Christy also mentioned that ARC has a helpful presentation on how to become a PASA. See below for the link to the presentation.

Becoming a Program Approved Service Agency (PASA):
www.thearcofco.org/advocacy/pasa.php

Carol Meredith offered an alternative path to becoming a PASA. Family members can become certified nursing assistants (CNAs) and work through an agency. This issue comes up in a lot of different meetings. Across the board, there are capacity issues. Part of it is what Candace talked about, which is the unemployment rate in Colorado is the lowest it's ever been. For example, McDonald's is hiring at \$12 an hour.

Carol also said there is not a way to track Prior Authorization Requests (PARs) that go unfilled. For example, a PAR says a child is eligible for 48 units of respite. Did someone in fact provide services to this child? There is not a way to track a PAR that the case manager never found a provider. The ARCs have asked the alliance to collect info from CCBs on which PARs are not utilized.

Candace Bailey pointed out that service planning is different than the PAR. The service plan is what is meant to capture the entirety of the needs for the client. Candace wondered if there is some way to pull data on the number of service plans from the system as a whole. That's only if case managers (CMs) are documenting the needed services within the service plans. CMs should know how to document service plans, but



there's turnover and other issues. The service only goes on the PAR if there's a provider. That's where the two connect.

Tiffani Domokos brought up the recent guidance from the Department on utilization. CMs are being directed by the Department to make sure utilization is at 100%, by changing either the PAR or the service plan. So it could look like 50% even though it's not. Even with hard data, it doesn't tell why services on a PAR are not being utilized. At Developmental Pathways (DP), the agency is digging into the data for why. DP tracks all the requests for proposals (RFPs) that go out, that don't get placed, or that get withdrawn. Sometimes there are providers that respond, but the families don't choose them. DP is working hard to dig into the why, of what's actually going on in the data.

Christy asked Tiffani to attend the meeting next month, as Tiffani's knowledge would be very valuable for doing a brainstorm and action plan. Christy also asked everyone to noodle on this topic during the month.

Cynthia Chapman said that she has come across PARs where children are being denied. This is from Pueblo and Colorado Springs. On the PARs that are submitted, they're being denied totally as not medically necessary. A lot of the parents don't have the time to go through the appeal process. Christy Blakely asked to follow up with Cynthia after the meeting to get more details on those cases.

2. Old Business

a. Pediatric Behavioral Therapies Update: Lindsay Westlund, Candace Bailey

Candace Bailey said the Department is making progress transitioning clients to Early and Periodic Screening, Diagnostic and Treatment (EPSDT) for Behavioral Therapies. The transition is due on June 30, 2018. The Children with Autism (CWA) waiver also ends on June 30, 2018.

Lindsay Westlund shared the transition will affect the DD, SLS, CES, and CWA waivers. In terms of transitioning, CMAs and CCBs have been given time to implement the transition. The latest transition numbers are:

- 91% of CES clients have transitioned to EPSDT.
- 92% of SLS clients have transitioned to EPSDT.
- 85% of DD clients have transitioned to EPSDT.
- 72% of CWA clients have transitioned to EPSDT.

Candace Bailey cautioned that the CWA waiver seems low, but it's a smaller number. Several children are going to stay on the waiver until the end. These families are aware of what is happening with this program. The Department has sent out multiple communications, and Lindsay is individually calling case managers.

Beth Cole asked how many children on the CWA waiver will not continue to qualify for



Medicaid. Candace Bailey answered that the Department does not have an exact number because family income is not required for children's waivers.

Christy Blakely said this conversation is exactly why this meeting happens. Because oftentimes, family get stuck at the county or someplace they shouldn't be. Candace Bailey clarified that it's helpful to have parents' information, but it's not required.

Chris Russell shared that the overwhelming nature of 24 pages of data causes some families not to finish the paperwork. Every single thing has to be filled out. If it's not required, it's very daunting, frankly. It's very confusing to people because the interChange has all this extra information. When they have applied for the Children's Home and Community-Based Services (CHCBS) waiver, and they get a paper that says they don't qualify for LEAP. Then the families call because they're confused.

Candace Bailey agreed that the system is not perfect. Candace suggested the two of them have a conversation offline about how to address that. Chris Russell said she meets a lot parents who don't want to tell people about their income.

Erica Wolcott also said the issue recently came up at her agency, which wasn't requiring that families enter information. The child's income gets them approved for MAGI and then they're denied from the waiver.

Carol Meredith also shared an issue where there's a child that needs Medicaid, the system puts people into Child Health Plan Plus (CHP+) instead of the Medicaid Buy-in. Candace Bailey agreed that it's system glitch that needs to be addressed.

Christy Blakely suggested a follow-up topic for another meeting should include what Medical Assistance (MA) sites are requiring, and what the correct requirements should be if the sites are mistaken. Christy also suggested the Medicaid/CHP+ mix-up scenario should also be on an agenda.

b. Waiver Updates: Candace Bailey

Below is a link on waivers.

Premiums, Expenditures and Caseload Reports:

www.colorado.gov/hcpf/premiums-expenditures-and-caseload-reports

Candace shared that the Department is working on a format for the renewal of the IDD waivers. The Persons with Developmental Disabilities (DD), Children's Extensive Supports (CES), and Supported Living Services (SLS) waivers are up for renewal next year. The Department will begin a stakeholder engagement process. The DD/SLS waivers are also in the process of being consolidated, and therefore there will be no substantive changes to those waivers for the renewal. If there's something minor that does not have a fiscal impact, the Department would like to hear about it. The meetings will be held between July and October of this year. The Department will break it down



by appendices for each meeting. The schedule and dates have not yet been set, but more information will be coming.

Christy Blakely explained the meeting has been discussing waiver consolidation for two years. Christy used the metaphor of a Medicaid house, with each waiver being a different door to enter the house. There's a lot of administrative overhead for each waiver. Colorado has ten different doors, for most states, it's maybe two. Colorado got real creative, and the state has lots of waivers.

Adam Steinbrunner asked how people can attend the waiver redesign meetings. Candace Bailey instructed him to email Josh Negrini at joshua.negrini@state.co.us. Christy Blakely encouraged Adam to attend.

c. Respite Discussion Continued: Christy Blakely

Christy Blakely repeated the Easter Seals information from the previous meeting. The facility is open for respite on weekends, from Friday night through Sunday afternoons. They will take children on CES waiver, private pay, and scholarships for CLLI waiver. There are also scholarships available for high medical needs at Hayley House. The respite includes two nights of respite. Their center is in Lakewood. They are now set up for the respite program. The facility also has a pool.

Brianna Carruthers asked if Easter Seals plan to do respite for the holidays. Brianna is also a nurse in intensive care. She sees children who don't have respite at the hospital, and the children end up going to the hospital for holidays, which is a huge cost. It happens a lot. Brianna also asked if Easter Seals could accept patients from Wyoming.

Christy Blakely said she would check on the answers to both of Brianna's questions, and add respite to the agenda for next month as well.

Carol Meredith said fixing the respite problem is difficult. Even though it's a waiver benefit, part of the problem has to do with the licensing. Many providers tell her that they couldn't make it work financially. There's a certain number of hours and training and supervision that has to be provided for employees. If a family only needs respite for eight hours a month, the reimbursement may not enough money to cover all of the training and supervision. Some children with high behavioral needs need two-on-one care, which requires a higher level of care with two people in the home. The rate does not allow that level of reimbursement. Because respite by design is periodic, it's just here and there, and that's what makes it so difficult.

Christy Blakely said respite and PASA will be on the agenda for next month. Christy suggested barriers and solutions brainstorming. For example, licensing, rates, and staffing are barriers.



Candace Bailey offered to provide a chart or table for children's waivers that have respite with the rates. For example, CLLI offers different levels of respite. The Department can put together some sort of table that would illustrate what's currently in place.

Christy Blakely shared that Easter Seals is calculating they are going to run respite as a loss. They're going to have to have a nurse available. If they bill at \$400 for two nights, they're still running at a loss.

Carol Meredith shared findings on respite from her work with crisis intervention around children with IDD and mental health diagnoses. At a minimum, families need to have scheduled respite. That is not available under the current system. Therapeutic respite is active treatment and intervention. For example, when children change their medication, the family is supposed to handle it after being discharged from hospital after a week. It's a lot to handle, with severe side effects from anti-psychotic medicines. It's clearly a dangerous situation we're putting these families in, and the therapeutic intervention type of respite is something we haven't figured out.

Carol continued that the Waiver Implementation Council (WIC) is looking at developing a good definition for therapeutic respite. Carol has been on the council for several years. She encourages people to access the information online. She sends input directly to Josh Negrini. This is going to the center of future waiver consolidations, and future waiver rewrites. The council wants to get it as right as we can the first time around.

Candace Bailey shared that one of the things is that the Department is working on with the WIC and waiver redesign is a definition for some of the services. For example, there is more than one definition for personal care for the waivers. It will not be a one-size-fits-all, but the Department can take what the WIC and waiver redesign team create as a blueprint and put that in all the different waivers. The Department wants to streamline the process so if a client need personal care, they get personal care in the same way no matter what waiver.

Carol Meredith also said people don't have to go to every meeting of the council. Josh is happy to provide documents from the meeting. It might behoove us to spend some time at CDAC to go over some of the future changes for the children's waivers.

Christy Blakely also made one additional announcement about an organization called Colorado Consumer Health Initiative. If a family is having trouble with private insurance, they can call the initiative. They are having a launch party for the Colorado Consumer Health Initiative (CCHI). Christy encouraged people to come or share the information. There are families that are having difficulty with insurance. There's a huge need. See below for link to CCHI.

Colorado Consumer Health Initiative (CCHI):

www.cohealthinitiative.org



Chris Russell suggested an item for new business next month on truly understanding transitional Medicaid. Chris said the topic makes no sense to her, as the portal jumps back and forth often with different results.

Christy Blakely said the group will find someone to talk about it, either next month or the month after that. Christy also said she will keep private-duty nursing (PDN) on the agenda. I will have someone talk next month or the month after that.

Carol Meredith also asked if billing issues could be added to the meeting agenda for next month. Candace Bailey reminded everyone the Department is not allowed to tell providers how to bill, per federal regulations.

Carol Meredith suggested CCHI could perhaps tackle that topic instead. Carol also asked for a progress report on the CHRP rewrite.

Candace Bailey shared that an internal CHRP team has been meeting weekly since the bill was signed on April 30, 2018. Administration for the CHRP waiver will move to the Department. Nancy Harris is moving to Health Care Policy and Financing. The Department is working on redesigning the services. This will include removing the requirement that a child be in foster care and adding an in-home stabilization and transition service. The timeline is ambitious. The Department is meeting internally on how to structure and coordinate all those pieces. Michele Craig and Candace are working with the assistance of a Lean team.

Carol Meredith asked if the Department was going to do a benefits collaborative. Candace Bailey said the Department might do so, but faces a truncated timeline. The Department is looking at it to see if it can work. The biggest hurdle is how to ensure all the right people are at the table – without overdoing it.

d. Legislative Updates: Carol Meredith

The legislative update was skipped this month due to lack of time.

3. Adjourn

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

