



**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.*

July 11, 2018
 10:00 a.m. to 12:00 p.m.
PHONE: 720-279-0026
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Introductions

In the Room		On the Phone	
Person	Agency	Person	Agency
Christy Blakely	Parent Advocate	Jessica Thayer	Colorado Access
Tiffany Rathbun	Developmental Pathways	Alicia Maestas	CDRC
Lindsay Westlund	HCPF	Matt Cloven	Arc of Larimer
Nina Snyder	HCPF	Shilo Carson	North Metro Community Services
Beth Cole	Early Intervention Colorado	Allison Harris	Tennyson Center
Chris Russell	PPHC	Gina Robinson	HCPF
Carol Meredith	ARC	Erica Walczak	JeffCo
Jyoti Sapkota	DHHA	Alex Koluskus	HCPF
Bethany Pray	CCLP	Brigitta	Parent Advocate
Ryan Zeiger	PASCO		



Agenda Items

1. Meeting Purpose

This is a positive meeting to brainstorm on issues related to children's services.

2. New Business

a. Action Planning Document: Lindsay Westlund/ Christy Blakely

Lindsay Westlund from the Department shared an action planning document. Christy Blakely developed the document based on the last meeting. Lindsay asked for feedback on the document. Lindsay specifically asked if the document was helpful. Lindsay also asked if items should be added or taken away from the document.

Chris Russell said she didn't totally understand the document. Beth Cole said there were a lot of issues with private-duty nursing that she hoped to explore.

Lindsay Westlund assured Beth private-duty nursing was on the agenda for the meeting. Alex Koloskus from the Department will be on the phone to discuss the issue.

Christy Blakely reminded attendees that part of the conversation last month started with a discussion of how many referrals she received as a Program Approved Service Agency (PASA.) With the reduction of contracting with the CCBs because of conflict-free case management, Christy said she is concerned there won't be enough system capacity to provide the services that are needed. Christy said she is worried that families waiting for services will be squeezed out with this change. With this action-planning document, Christy said she was trying to get at some of the problems and strategies. Christy also left room for some more issues that will come up.

Ryan Zeiger shared his experiences as a PASA at PASCO, which provides services under multiple waivers. The respite services are the ones that are extremely challenging. Ryan asked if the conflict-free case management was driving the changes.

Carol Meredith offered that the Department of Labor (DOL) rule changes also had an impact. For example, Developmental Pathways stopped contracting five years ago. Rocky Mountain Human Services was taking contracts. The main issue is that it's a DOL rule.

Ryan shared his experiences with the DOL. DOL surveyed PASCO shortly after Ryan started there. They really dug in and asked why we had people as contractors. The DOL said we had to employ them unless they bill multiple people. It was very clear they were out to dig into that issue. The DOL were aggressively going after contracting.



Carol Meredith also said that happened with the ARC, which was contracting with one person. Christy Blakely agreed that above and beyond this action plan, the group also needs to get to the root of why this is happening.

Chris Russell said both DOL and the Department are driving the changes. In her meetings with Dennis Roy, there was talk about this conflict-free case management. The idea that a Community Centered Board (CCB) was qualifying people for a waiver, and then sending people to services at the same CCB, would violate conflict-free case management.

Christy Blakely asked if anyone else on the phone could shed light on why this is happening. She asked if there was a specific rule. Carol Meredith offered to send Christy a copy of the DOL ruling.

Beth Cole jumped in with an anecdote about The Resource Exchange in Colorado Springs. The Resource Exchange pulled their early intervention contractors and made them employees. The Resource Exchange got fined by the DOL.

Carol Meredith praised the document, but she suggested broadening its scope. These issues are reverberating throughout the system of care for children with disabilities and their families. Carol suggested framing it as a problem solve in a more general perspective, instead of this specific issue.

Christy Blakely said they could make the document broader in scope. Carol Meredith continued that licensing becomes an issue for people who want to become a PASA, specifically a Home Health A or B license.

Ryan Zeiger clarified that Class A is for private-duty nursing, skilled labor, and medical services. Class B is for unskilled labor, non-medical services, and services under the waiver. Ryan said he believed PASA had to be Class B.

Carol Meredith explained the requirements under the licensing are impacting training and staffing. Licensing and the costs associated with licensing are becoming cost-prohibitive. Just to get the license costs money. She has seen many providers who were providing respite to kids who said they can't afford it anymore.

Carol Meredith also brought up rights modification, which is a change in the way the Office of Community Living is talking about waivers.

ACTION ITEM: Lindsay Westlund offered to put rights modification on a future agenda item. She will get someone with expertise in that subject matter to speak to the group.

Christy Blakely said the group will look at respite with a magnifying glass. There are not enough providers with services to help everyone who needs to get services.



- Is it the licensing issue?
- Is it the DOL coming down on contractors?

Christy said the group needs to figure out where families are going to go to get these services.

Tiffani Rathbun clarified that CCBs aren't going away -- they are going away as providers. Christy Blakey agreed that CCBs are no longer contracting for the services.

Ryan Zeiger shared that he could start putting things in these buckets as a provider of respite for Children's Extensive Services (CES.) A child with somewhat complex needs has both Certified Nursing Assistant (CNA) needs and nursing needs. The issue is that PASCO still has to send out a nurse out to train every new provider. It's not a bad idea, but that individualized training makes it hard to train staff on low-frequency services. Sending out a Registered Nurse (RN) is expensive.

Christy Blakely commented that it often comes down to reimbursement.

Ryan Zeiger agreed that reimbursement is part of it, but it's also the low frequency. Respite is not that frequent, but PASCO has to train new respite providers frequently. Perhaps they can be a certification instead of individual training for a nurse, so agencies have to send out a nurse for non-nursing skills.

Chris Russell asked if it would be possible for a skilled nursing agency to get paid for respite for a regular visit. Ryan Zeiger said skilled nursing is doing that nursing and then leaving. Ryan pointed out that the Children with Life Limiting Illness (CLLI) waiver has broken out respite levels. However, CLLI doesn't have a lot of people.

Tiffani Rathbun shared that Developmental Pathways has tried combining needs. For example, the agency worked with providers to find someone who can do three nights a week -- one night a week for one family and two nights a week for another family. Sort of a hodgepodge to make everyone happy. The provider is guaranteed three nights a week for consistent income. Meanwhile, families also receive the care they need.

Carol Meredith agreed that combining needs works in the Denver metro area, but will not work for rural areas. The group provided that the respite chart was a very helpful tool. Lindsay Westlund made sure to credit Kathleen Homan from the Department for her work on the chart.

Ryan Zeiger also outlined the benefits of regular respite. One thing is to get families on a regular schedule for respite because it makes the family happier. Because of the lack of frequency, some families cancel a fair amount. It's very different from the consistent services PASCO provides on a daily basis.



Christy Blakely pushed back on that idea. Is it because families don't get enough services? If families only receive respite for four sessions a year, that's quarterly.

Ryan Zeiger shared data on respite that showed a high underutilization. If agencies authorized people for 30 days of respite, would there be a higher level of utilization? There are a number of reasons for families not utilizing respite, per the group.

Beth Cole shared her experiences serving on the Colorado Respite Coalition. One of the reasons that people declined respite is that they weren't comfortable with the respite provider. Tiffani Rathbun wondered if there will be a change with behavior not being in the waiver anymore. Maybe families can use their budget for respite instead. Carol Meredith pointed out that people prefer to use Supported Community Connector instead of respite because the reimbursement is higher.

Chris Russell contributed that she has been attending the Respite Coalition Services. The organization is going to launch a chart with who's available for respite, and how much it costs. They have 100 people on their waiting list for scholarships for respite. They've really been pushing to make things much clearer.

Christy Blakely also brought up that transparency is key. People don't always understand the different levels of respite, or the different hours of training for respite providers for the different waivers. Often the training is very generalized.

Ryan Zeiger also pointed out there's also some things in the system that provide respite that aren't necessarily called respite. For example, the CNA coming in three days a week to give showers gives a care giver a brief break.

ACTION ITEM: Christy Blakely suggested someone could look at the respite requirements for training and see if the training could be streamlined. Ryan Zeiger suggested projecting the information (the action plan document), while Carol Meredith said Adobe Connect could be used for people on the phone to set up a more interactive meeting.

Christy Blakely said the group would do that in one of the next four months. There's a projector here.

Carol Meredith brought up her findings from the Community of Practice webinar. Throughout the state, wraparound workers are saying that CES is so hard to get it's not even worth it. And that's a problem. If child welfare workers and families are saying it's too hard, that's a big problem.

Chris Russell agreed that it's a huge problem that the application went from eight pages long to 43 pages long. It's a real deterrent.



ACTION ITEM: Christy Blakely suggested inviting representatives from the Department, a CCB and someone from a county to discuss that issue at an upcoming meeting. If it's too arduous to get CES, the Department needs to reduce those barriers.

Christy Blakely also said it's a problem in the rural areas because they don't do it as often, they don't know how to fill out the paperwork.

Brigitta said she would like to speak to this issue. Brigitta came from another state, and it was much easier. She doesn't understand how the State of Colorado can make this so complicated. Christy Blakely shared her experience with other states with waivers. In Illinois, she never saw the money, but she just got respite for so many hours.

Brigitta said that the group can all agree that simplification can also make some of the processes cheaper. That is just a perfect example of government waste. Nina Snyder asked Brigitta where she lived before Colorado. Brigitta said she was from Iowa. Brigitta also emphasized that Colorado is a much wealthier state than Iowa.

ACTION ITEM: Lindsay Westlund offered to send out information on parental fees.

Lindsay Westlund shared that the Department wants to simplify and streamline waivers. The Department needs experience from people in other states. Please come to other stakeholder meetings. CES is also going to start being discussed. Obviously, there's lots of comments about CES services.

Christy Blakely shared that CHRP is going to be done in 2019, as is DD and SLS. Christy suggested the group spend another hour next month really digging into the CES waivers. The group can also assign Candace a whole bunch since she's not here today.

Carol Meredith said she'd like to make sure some folks from different cultures can speak at the meeting. There's opportunity for the applications to take into consideration other culture's perspective of this process and questions.

Christy Blakely likened the application process to be like "going through your underwear drawer." And if parents are from a different culture or there's a language barrier, it can seem more invasive.

Carol Meredith said she could ask one of my staff members. She is from Colombia and just got on the CES waiver.

Brigitta offered that she is white and college-educated, and she is still baffled by this system. Brigitta has been working on this for several months, and feels like an idiot. She offered to invite her friend from Mexico who has a son with profound autism. She's trilingual so I don't think she would be intimidated.



Christy Blakely said the meeting might require cinnamon rolls or something yummy because that's going to be a hard agenda. Brigitta asked if the group could push that out to September instead of August because it would be easier for parents who are home with their kids.

Christy Blakely said September would be fine. Next month, the group can focus on the action-planning document for an hour. In September, the group can work on CES and eat the cinnamon rolls. Brigitta also agreed that will give more time to invite people.

3. Old Business

A. Respite chart: Christy Blakely

Christy Blakely asked meeting attendees to look at the respite chart with different reimbursements. Beth Cole asked about the unit rate of \$1 for camp. Tiffani Rathbun explained that a camp would say that camp costs \$575. Then the agency would put it in 575 units to make \$575.

Beth Cole remarked it's an interesting way of doing that. Chris Russell asked who determined the cost of camp. Ryan Zeiger answered that the camp determines the rate.

Carol Meredith remarked that it's interesting to me that in-home respite is paid at the same rate in all non-DD waivers, but it's less than what CES is paying. CES is at \$5.07 for 15 minutes.

Christy Blakely asked why the rates are in 15-minute increments. Chris Russell said they don't want to pay the same as two hours as for one hour and 45 minutes. That's the same for other insurance providers. Ryan Zeiger said two hours is probably the least amount of time for respite.

Some discussion followed on the different reimbursement rates. Beth Cole said when the rate advisory review committee meets, they're just looking at specific codes. Christy Blakely commented that the CLLI waiver does 4-hour increments. Christy suggested the 4-hour increment could be put in CES.

Lindsay Westlund shared that at some of the other stakeholder meetings, the Department brings in someone from the rates section for discussion and offered this as an option to the group. Christy Blakely stated that they could determine at a later meeting if this would be necessary.



B. Pediatric Behavioral Therapies: Gina Robinson

Gina Robinson shared the latest updates on Pediatric Behavioral Therapies. With school getting out, The Department had a jump to 563 members. Only one member switched providers. The Pediatric Behavioral Therapy list needs work. Gina asked meeting attendees to reach out if they have any ideas of how the list should look.

Ryan Zeiger asked what the problem was with the list. Gina answered that people wanted providers to list if they were in network or out of network for each insurance.

Gina Robinson continued that providers have reached out to her and shared that they have no waiting list. One provider has a six-month waiting list, but Gina suggested the provider make referrals to other providers. Gina shared that some providers are not available during the times parents want appointments.

Carol Meredith said it really helps when Gina send those communications out, and also when the providers put the geographic area. Gina said she agreed that geographic area helps when the parents are looking for providers. Some providers do statewide, which makes it difficult to search for them.

Christy Blakely updated the group about a very active group she discovered on Facebook for parents of special needs. Some parents are sharing information that is not correct. It's another place we need to put things. They are not on Parent to Parent, or they're between Medicaid and insurance.

Beth Cole asked for the name of the group. Christy answered the group is called [Denver Special Needs Parent Community](#). Somewhere in the process, Maureen Welch stepped in to help. A lot of questions are posted, not all queries are critical questions. Christy has been trying to answer the critical ones.

Lindsay Westlund reminded everyone that the CWA waiver ended on June 30. We are also wrapping up the behavioral therapies transition. She has been in communications with the CCBs, and she's just waiting for final information about these transitions.

Beth Cole asked if there is a list of kids who are no longer eligible for services.

ACTION ITEM: Lindsay Westlund offered to look into that question.

Christy Blakely opened up the floor for questions. Allison Harris took the opportunity to ask about two new codes she found when submitting a PAR.

Gina shared that there is a provider trying to get summer camp and skills-building covered. Any codes they ask for have to be added, even if they're not approved. The Department is still looking at the requests for group services.



Carol Meredith asked why skills building not on the list. Gina answered that it's been that way since day one. Skills building is educational in nature rather than medical in nature.

Carol Meredith said there's a system called the Skills System that's more like a cognitive behavioral system. The system includes self-calming strategies. That's not taught at school. Gina agreed that something like that could be requested, and the Department will review it. Skills-building and camp are two exclusions, so we have to look at that.

Carol Meredith offered to talk about that at the Benefits Collaborative next meeting. Many times, in order to teach a replacement behavior, children have to do skills. If children can fill up the day with something that's an appropriate thing, children don't have time to do the inappropriate thing. Gina said she agreed.

Chris Russell asked if the Department will publicize it if the Department approves that code. Gina Robinson said no because EPSDT exceptions don't mean new benefits, it's a case-by-case exception.

Christy Blakely asked for updates on private-duty nursing. Alex Koloskus shared that the Department is in active litigation in district court regarding the 16-hour limit, so she can't comment on it. The Department asked all case management agencies to send us a list of their clients ages 16-20. The Department cross-referenced that with a data pull from EQ Health. The Department also pulled claims as a third check to see what's been billed for by the agencies. On August 2, the Department will have a presentation on that at the case managers meeting. The presentation will get everyone on the same page to ensure that case managers are having discussions with clients much earlier about what their options are regarding PDN at those levels.

Chris Russell pointed out that she's had families who are not getting 16 hours because they are not being able to be staffed for 16 hours due to the nursing shortage. It's important to keep in mind that the number of hours families are receiving may not be the number of hours families *need* to have.

Alex Koloskus said the Department is looking at more individuals with more details. Alex appreciates that there is a nursing shortage for even the 16 hours. That's another thing we have to be aware of at the Department.

Christy Blakely asked Alex to keep the group informed. Alex Koloskus offered to give another update after the August 2 quarterly call.

Chris Russell brought up a difficult case of a family in Weld County. The mom is 80 and has pancreatic cancer. The daughter is 56 years old, and has a ventilator at night. Chris reported staffing the family for 12 hours a day. This is the worst-case scenario. The



case manager told the family in error that they can't get In-home Support Services (IHSS.)

Chris Russell said she is first delicately discussing writing a plan for when the caretaker is gone. Group homes are not an option for ventilators.

Ryan Zeiger shared that there is an organization called [Premier Medical Corporation](#) that serves people with ventilators and trach tubes. They may be worth talking to for that case.

C. Meeting Report Out:

Ryan Zeiger shared that there's an IHSS work group that he attends, and there are some rule changes as of May 1. There's been an increase in provider agencies for IHSS. There are 130 agencies. There's also been a growth in utilization. Per Ryan, the Department reported at this meeting a need to train providers and ensure appropriateness of services being utilized.

4. Adjourn

Christy Blakely moved to adjourn. Christy said she appreciates the time and attention for all the kids in the State of Colorado because they're pretty special.

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.

