

OPEN MEETING MINUTES

| | | |
|--|---|---|
| Name of Governmental Body: Council for Children with Long-Term Support Needs | | <p>Attending: Attending: Wendy Heyn, Parent (Chair); Patti Becker, Parent; Kelly Blaschko, Provider, Genesee Community Services; Kerry Blondheim, Provider, Innovative Care Services, Inc.; Anouvong “Toto” Chanthavixay, Milwaukee County Children Youth & Family Services; Christina Courtney, Brown County, LTC PAC Representative; Lisa Hankes, WI Department of Children & Families; Pamela Hencke, Parent; Michelle Mattox, Parent; Angela Milne, Provider, Executive Girl Friday; Katy Morgan-Davies, Parent; Marianne Novella, Parent; Cherie Purdy, Parent; Angela Radloff, Dane County Human Services; Walt Schalick, Provider, UW Hospital; Jessica Seawright, Parent; Lisa Stephan, Manitowoc County; Beth Swedeen, WI BPDD; Sandra Tierney, Parent; Danielle Tolzmann, Family Voices of WI; Jamie Willett, Parent; Elizabeth (Liz) Williams, Parent; Windsor Wrolstad, Disability Rights Wisconsin</p> <p>Council Members excused: Anne Dent, Parent; David McGinley, Parent</p> <p>State Attendees: Deb Rathermel, BCS; Kaycee Kienast, BCS; Andrea Warman, BCS; Tara Sommersberger, BCS; Tip Pom, BCS; Beth Gullickson, BCS; Zach Bauer, BCS; Samella Jolly, BCS; Allan Goetsch, BCS; Becky Granger, BCS; Nancy Bills, BCS; Willow Wallis, BCS; Molly Tull (Notetaker), BCS; Olivia Antlfinger, BITS (AV Support); Michelle Lund, DHS</p> <p>Public Attendees: Amie Bastian, Outagamie County; Jill Jacklitz, Executive Director, Disability Rights Wisconsin; Autumn Jalinski, Portage County; Paul Mross; Vickie Smith, Waukesha County; Tanna Spence, Danielle Bauerr, parent</p> |
| Date: 5/14/2025 | <p>Time Started: 9:05 AM</p> <p>Time Ended: 3:07 PM</p> | |
| Location: Holiday Inn at The American Center, 5109 West Terrace Drive, Madison, WI, OR via Zoom (morning session only) | | Presiding Officer: Wendy Heyn, Chair |

Minutes
Welcome – Wendy Heyn (Chair) and Deb Rathermel

- Council Attendance – Wendy Heyn
 - Council Member Announcements
 - Beth Swedeen –BPDD (Wisconsin Board for People with Developmental Disabilities) just got rest of funding and will be able to keep operating; of note that 6 Partners in Policy Making grads in attendance at today’s Children’s Long-Term Support (CLTS) Council.
- [CLTS Council Membership Roster](#)
 - New Member Jessica Seawright – Parent member and provider for professional services group
- New BCS Section Manager
 - Kaycee Kienast is new Program Improvements & Quality Outcomes Section manager
- Federal Medicaid and U.S. Department of Health and Human Services Update
 - There are federal and state budgets – both are in flux right now
 - Federal funding for much of what we do comes from CMS and is Medicaid money
 - Wisconsin Medicaid is about 60% funded federally and 40% funded by the state
 - Right now, there’s a lot of attention on Medicaid funding at federal level
 - Sunday night, May 12, 2025 the House Committee on Energy and Commerce released proposed budget reconciliation text that make cuts to Medicaid
 - Many of the changes to eligibility are aimed at “able-bodied adults without dependents”
 - Addition of work requirements
 - Will make it more complex for some people to get Medicaid coverage
 - Wisconsin’s funding formula for non “able-bodied adults without dependents” doesn’t seem to be impacted by change
 - Governor Tony Evers named 2025 “The Year of the Kid,” and the Bureau of Children’s Services (BCS) asked for some additional support: Get all eligible children enrolled and served by CLTS; continuing support for Wisconsin Wayfinder – both were removed from the budget by the state legislature
 - Making CLTS an entitlement program would take budgetary risks away
 - Federal budget must pass to avoid shutdown
 - Wisconsin must pass budget by July 1 – won’t be shut down, but would have to continue under FY2024 budget
 - Beth Swedeen – Explained how proposed federal changes could negatively affect people with disabilities and caregivers; most states don’t have budget to do required oversight
 - Department of Agriculture is also reviewing SNAP (Supplemental Nutrition Assistance Program) – 2/3 of people on SNAP use Medicaid; cuts would be about 30%
 - Proposed removal of federal funding to all auxiliary/local funding (ACL) to support people with people with disabilities (article about issues available on Board for People with Developmental Disabilities, or BPDD, webpage); US Health and Human Services Secretary Kennedy has already dismantled all administration for community living (not being put in other places); community living programs aren’t just better for people served but also more cost-effective than institutions
 - Patti Becker – ACL services are through federally funded grants
 - Beth Swedeen – BPDD has regular meetings to discuss these issues (wi-bpdd.org); people have to register to attend the meetings, but get access to recordings
 - Deb Rathermel – Important to make sure you’re getting accurate information
 - Katie Morgan-Davies – Are there other opportunities to get more involved? This is so important to council members
 - Facebook groups, Hands Off Medicaid [Congressional District] as grassroots
 - Learning My Shoes (educational group)

Approval Of Minutes

Motion to pass minutes required from February 5, 2025 (<https://www.dhs.wisconsin.gov/cltsCouncil/clts-minutes-20250225.pdf>)

MOTION TO APPROVE: Walt Schlick SECOND: Kerry Blondheim

Public Comments

- Danielle Bauer: Interested in timely enrollment initiative and when she can ask for CAP (corrective action plan).
 - Deb Rathemel: Will process CAP request as Open Records request.

CLTS Data – Kaycee Kienast

- Summary Enrollment and Disenrollment Q1 (first quarter) 2025
 - CLTS enrollment has been steadily growing
 - Currently averaging 484 newly enrolled kids every month in CLTS
 - Disenrollment higher in fall of 2024; this is due to helping kids transition to adult services
 - 2023 jump in disenrollment due to ending of the public health emergency (PHE)
 - Main disenrollment reason is transferring to adult long-term care (LTC), family no longer accepting services (system doesn't collect why), transfer to new waiver agency, not functionally eligible, suspended (most likely a settings issue until they leave facility), moved out of state
 - Danielle: How do you decide a family is no longer accepting services?
 - Deb: Sometimes they stop communicating with program, sometimes they say they don't need/want the services anymore
 - Question: How likely is it that families get "lost" by county – change address, phone numbers, etc.?
 - Kaycee: Not likely. Counties all have processes to keep in contact.
 - Deb: Most people who disenroll do it within first six months. Seems that they just decide program isn't for them.
 - Katie Morgan-Davies – Wondering about reasons between labelling "Not receiving services" vs. suspension, which would seem less final.
 - Kaycee – There is new category that meets this need, but it didn't make top six reasons
 - Question: Why would family say they don't want services?
 - Kaycee – Not currently tracking, but there could be many reasons.
 - Question – Could there be better education about program?
 - Some people don't want this level of contact, some don't feel the program can help them, etc.
 - Do still know about program if they ever need it.
 - Comment – Some parents of kids with autism don't find it what they need. But parent groups do recommend that people enroll, just to see what the program is all about. If you leave program, do you have to re-enroll.
 - Answer – Yes, but functional screen is good for a year.
 - Question – What is it when child is eligible but not enrolled?
 - Deb – child has been found eligible, but hasn't gotten an individual service plan (ISP), etc., so isn't fully enrolled and funded. There are generally about 1000 kids in this situation at any time.
- Summary Data Appeals Q1 2025
 - 20 appeals filed Jan-Mar 2025
 - 13 eligibility appeals
 - 7 support and service appeals
 - Question: What supports and services most likely to be appealed?
 - Deb: Not sure if there's any theme.
 - Kaycee: Will take this back to look at.
 - Appeals data will be more complete as we gather more information
 - Question: Will you continue to publish decisions online?

- Deb: Division of Hearings and Appeals (DHA) makes that decision, and they seem to be continuing practice.
- Suggestion that families be more supported in following all the steps for program, etc., so that they don't end up having to go through appeals process

CLTS Enrollment Timeliness Compliance Initiative – Andrea Warman

- Memo 2024-02 was released 8/8/24
 - Went into effect Jan 2025
 - Counties must meet enrollment timeliness
- 11 counties have CAPs
 - CAPs based on Nov 2024 data
 - One county had delay between 100-200 days
 - Eight had delays of 200-300 days
- Asked counties to analyze root cause of noncompliance
 - Program growth
 - Staffing levels
 - County board roadblocks
 - Navigating dual eligibility (CLTS and Comprehensive Community Services, or CCS)
 - Support and service coordination (SSC) rates
- Have had 64% decrease in number of children waiting over 100 days to enroll (Apr 2024-Mar 2025)
 - All counties have done significant amount of work to address issues
 - Question – What can council or activists do to support this effort?
 - Deb – Work with local county groups. Families and advocates can work to communicate with local county groups.
 - Danielle – Marathon Co. said there was nothing she could do as parent-advocate.
 - Toto – Milwaukee Co. has increased contracted agencies, noticed that they all had different rates and looked into that, continued with hiring new staff; provided some grant money to contracted agencies to boost staff; contracted new agency to work specifically with dual eligible kids; this has all improved their enrollment timeliness
- Continue to monitor data – some counties are almost into compliance

BCS Status Updates

- CLTS Transition Resource – Deb
 - Had to delay this release. Not ready yet.
- CLTS Participant & Family Handbook – Tara
 - Handbook is completed!
 - Danielle – The handbook is FABULOUS! Great work!!
 - Thanked Family Voices for helping put BCS in contact with families to help with input
 - Handed out hard copies to attendees who wanted one
 - All currently enrolled CLTS Participants receive handbook in English, Hmong, or Spanish (depending on preferred language)
 - Question – What are you hearing from SSCs, families, counties, etc.?
 - Tara – Have gotten really positive comments.
 - Handbook will be updated annually – will always be available online
 - Updates will be online and announced in AIFK
 - To do another mass mailing, update would have to be a very major update
 - Question – One parent didn't get handbook
 - Tara – Addresses are being pulled from ForwardHealth – will look into it
 - Some counties are asking families if they received it and what they think

- New CLTS Claims Processing System – Tip
 - On 4/28, ForwardHealth (FH) Portal started accepting claims
 - First payments issued May 12
 - CLTS Operations Team now provides support
 - Expect claims submissions to go up as more providers start submitting to FH
 - Deb – We are heavily invested in getting all providers over hurdle to be able to sign into Portal and submit claims
 - Danielle – Family Voices decided to jump in and register as provider in middle of all this and found it incredibly smooth and easy
 - Christina Courtney – Still haven't seen conversion of prior authorizations (PAs) in WPS files to FH Portal. Families are relating that providers aren't being paid. Will this be taken care of soon?
 - Tip – There is a difference between the way PAs are done. Working with Gainwell to fix. Started with over 80,000 unmatched; should be another spreadsheet going to counties this week; number of unmatched PAs has gone down significantly.
 - One suggestion to call the number – wait times weren't too long and they did help.
 - Deb – We will find the solution if someone contacts us CLTS Ops Team or escalates.
- Vickie Smith – Things are bumpy right now, but once everyone is using it and all the info is transferred, it will be much better for counties and providers.

Council member sharing and discussion

- Jill Jacklitz, Executive Director, Disability Rights Wisconsin (DRW) – Important to keep sharing experiences and educating policy makers on how important funding for services is. Money from HHS has been secured for 2025. Still awaiting word on other federal funding. Will keep fighting for full funding. Have worked with flat funding for many years, not reliant on grants. Making some changes to staffing that will move DRW in great direction. Part of funding is for victims' services.
 - Jessica Seawright – Are there specific state budget items that can be advocated for regarding victims' services?
 - Jill – Crime Victim Services is in biennial state budget, but not clear what that covers. At federal level, funding is also in flux.
 - Jessica S. – Should people include why this is important to them when talking to legislatures?
 - Jill – Yes. Especially talk about why it's important to kids.
- Kerry Blonheim – Struggling with uniform reimbursement rate for child care. Some ends up being less than minimum wage.
 - Elizabeth Williams – Child care for kids under 12 is very difficult. We can't pay \$7/hour and expect anyone to help. Especially hard for parents of kids with special needs. And summer programs can't always be used.
 - Danielle Tolzmann – When CLTS Program works well, it is great for families. However, families perceive that there is gatekeeping of types and amounts of services. Looking forward to conversations this afternoon.
 - Angela Milne – Getting information that respite rate levels for kids are being changed and that state is directing this. Is this something the state is doing?
 - Deb – No.
 - Jessica Seawright – Would like more transparency about HIPAA (Health Insurance Portability and Accountability Act) and problem solving with respite, child care, rates, etc. How do we educate families about what rates should be, etc.?
 - Jamie Willett – Has 12 and under always been parental responsibility for childcare?
 - Deb – Yes. BCS had to work with CMS to allow any child care with waiver funds, arguing that children with special needs over 12 are less likely to have parental responsibility for child care. Don't anticipate that we could fight for more in our next waiver renewal. But if what we got isn't that helpful to most families, should we remove it?
 - Jamie – Group day care won't take children with medical complexity, and this makes it so much harder to work.
 - Pamela Hencke – At Circles of Life last week, discussed paying people for respite and rates. Some people try to find different ways to pay their caregivers extra to keep them. Discussed how to get outlier rates. Gave examples of how to find caregivers. Need to think creatively about how to address need for service providers.
 - Jamie Willett – Can be hard to find caregivers who stay, even when fully staffed.

- Wendy Heyn – A lot of caregivers are young and move on to other things.
- Jessica Seawright – Is there way to appreciate and reward caregivers? A lot of people use informal networks to find them.
- Wendy Heyn – unsure where it says that parents can't pay caregivers extra.
 - Deb – It's in the provider rules. They can't accept more than the amount paid by the state.
 - Cherie Purdy – It's in what the provider signs.
 - Patti Becker - It's on the Medicaid provider agreement.
 - Deb – If they're paid through a fiscal agent, the agent is responsible for making sure they follow rules.
 - Pamela Hencke – If providers accept a gift card, etc., who's responsible?
 - Windsor Wrolstad – Listening closely and taking notes for future.
 - Angela Milne – Some families see the amount of paperwork and decide not to be involved.
 - Pamela Hencke – This is an issue. Families do worry about paperwork. Thinks this could be something else to help families with.
 - Jamie Willett – Families are also responsible for training their new caregivers, and it's time consuming.
 - Pamela Hencke – Provide some documentation to help walk families through training process.
 - Jessica Seawright – What are our options when we have these problems?
 - Wendy Heyn – Curious about who had smooth transition from CLTS wipes to card services. (J&B)

Overview and Council Orientation to Topics for Input – Deb

- Going to get overview of topics that will be part of roundtable discussions this afternoon
- CLTS CMS Waiver Renewal – Zach Bauer
 - Every 5 years need to reapply for the federal waiver to administer CLTS Program in Wisconsin.
 - Currently in early stages of renewal
 - Summer 2025: First step is to gather input from internal and external partners
 - Fall 2025: BCS drafts waiver application based on input
 - Spring 2026: 30-day public comment period
 - Summer 2026: Submit final application to CMS
 - Fall 2026: CMS review and approval
 - January 1, 2027: New waiver goes into effect
 - Considerations
 - Program growth and enrollment timeliness
 - Eligible populations – are we serving all populations well
 - In scope vs. out of scope: benefit package is in scope; payment model is out of scope
- Benefit Package and Service Descriptions including credentials
 - Splitting services into discrete definitions.
 - Clarifying service description
 - Self-direction – Strengthening/clarifying employer authority
- Danielle Tolzmann – Suggestion to post for comments before JFC review
- CLTS Service Provider Support and Technical Assistance – Tip Pom
 - Provider Qualification and Standards
 - State must provide for continuous, open enrollment of waiver service providers
 - CLTS providers sign Medicaid agreement
 - The Wisconsin Department of Health Services (DHS) approves all providers; counties can view qualification documents in Provider Registry
 - Recruiting & Retention
 - Providers can register very easily and will get listed on Provider Directory
- Consistency Across County Waiver Agency (CWA) & Support and Service Coordinator (SSC) – Beth Gullickson
 - Talking about consistency because BCS hears from families and council members that their experiences vary from county to county

- Want to get examples and ideas that can help support consistency while honoring local strengths
- Shared ground rules – positive intentions
- Shared areas of focus
- Shared questions to guide afternoon’s conversation

During afternoon session, there will be roundtables, and members can choose which discussion or discussions they want to be a part of.

Roundtable Discussion: Waiver Renewal – Zach Bauer

Service Package Changes

- Overall, council members suggested more clarity around the CLTS service package and make some services more explicit about what they cover.
 - With some services being too vague, parents and service coordinators are not sure whether something is covered or not.
 - This can lead to inconsistency across counties and different experiences with the program based on the experience level of the service coordinator
- Individual Service Issues
 - Grief and Bereavement Counselling—council members expressed confusion about how to get this service authorized
 - Others suggested being able to use this service when you enter the program for parents and family members to process their child’s diagnosis
 - Respite
 - Council members discussed confusion about times when to bill for respite or daily living skills services because some respite providers are working on skills while the child is in their care
 - Others discussed confusion about when to use the respite category versus when to use the childcare service
 - Childcare benefit
 - Council members described how the childcare benefit can be confusing and hard to get authorized for their children
- Service Rates
 - Respite Rate Levels
 - Council members discussed issues with the respite rate levels and how some parents were working to get their child authorized at a higher rate level to improve provider access
 - Other described how the rate levels can be useful because a “one-size-fits-all” rate could mean that children with higher needs may not get access to the respite providers
 - Other suggested a more standardized way of determining respite levels, like including it the functional screen
 - One council member suggested a bundled daily rate for “wraparound” services for children with higher needs
 - This would allow a services coordinator to work more easily with children with higher needs and reflects how much of the SSC work changes from day-to-day
 - Council members discussed outcome-based payments for providers
 - Some expressed concerns that these payments wouldn’t work for many services because outcomes can be hard to define
 - Others were concerned that the payment could cause providers to change their behavior or work toward only the outcomes that result in the payment
 - Others supported testing the model for one or two services where outcomes were clearly defined and tracked
 - Some county providers discussed whether there was flexibility to increase rates to account for provider transportation time, especially in rural areas
- Units of Services
 - One council member suggested a tool or formula that would help counties determine how many hours of respite, personal support, or childcare to authorize

- Some of the counties felt as if they could not limit some of these services when the families specifically requested them

Incident Reporting

- Some council members discussed issues with the incident reporting requirements
 - Some found the criteria to be overly strict or confusing
 - Other discussed confusion about reporting incidents that happen at schools
- Other council members discussed the cumbersome system used for reporting

Serving Different Populations within CLTS

- Council members discussed whether all target groups were being served well under the CLTS waiver and whether children with medical fragility would benefit from a different program that was suited to their needs
- One council member said that children in the SED target group may need more attention as much of the focus of CLTS is on physical health services
- Many of the council members agreed that children with medical fragility/complexity may not be receiving all the support they need through CLTS
 - Some said that service coordinators often are not equipped to work with this population or understand exactly what children with medical fragility need and what the family was advocating for
 - Others described situations of families they knew where they were only accessing respite through CLTS because their child was too complex for any of the other services offered
- Other council members expressed concerns about a new program for children with medical fragility
 - Some were worried that the children and their family would lose access to service coordinators or providers they like, or to the community of other CLTS participants
 - One council member was worried about access to providers and any additional layers of administrative work that parents would have to complete
- One member suggested providing access to a regional RN or medical professional with expertise with medically complex children that SSCs could reach out to, as an alternative to a new program

Other

- One council member suggested creating more standardized rules for parental payment limit billing and making sure that counties send a monthly bill to parents
 - They also suggested more education around the parental payment limit rules
- Another member suggested focusing on things that could help parents with multiple children
- One member suggested making people more aware of opportunities for parent and caregiver training

Roundtable Discussion: Service Provider Support & Technical Assistance – Tip Pom

Retention & Recruitment

- Providers are required to understand Sections in manual
- Barriers to medically complex and behavioral needs care – workers make too little
- Rates are a barrier – advocate for rate increases
- Relationships are key for families who hire DPSs directly to keep workers in place – how can families better build those relationships?
- Can we ask providers for market rates?
- Kids with complex medical care – they are at home, but payment is childcare rate
- Agencies do not have enough caregivers
- Alter fee structure? Pay people differently based on their experience and qualifications
- DHS Provider directory page – connect it to respite care list

- Provide more opportunities for ongoing training
- Connect more direct service providers (DSPs) to Wisc Caregivers List – link to DHS provider directory webpage
- Help families know they can refer caregivers they find to CLTS to become providers
- Issues with systematic no-shows – agencies don't fire those works and they bounce around to different families
- How can we increase the number of agencies that provide caregivers for families?
- CCS rate schedule – pays different rates, by credentialing code
- Explore use of broker services? (ex: Consumer Direct)
- Health Check and other services for providers – website for those new to /unaware of EPSDT

Qualifications (Quality)

- Encourage DSPs to do Wisc Caregivers training
- Providers choose services that “sound like” the service they do until they meet with county and then make changes
- Connect fiscal agents to WI Caregivers list for DSPs with more training
- People should be paid their worth – however sole proprietors are identifying market rates at high amount/level
- Providers that need license – may have multiple licenses and think they can provide all services
- How do we ensure non-licensed providers/DSPs are of high quality?
- Need more of a feedback loop between CWAs/SSCs/families about experiences with providers to build knowledge about which providers are high quality
- Quality issue - Limited options for CWAs to take action if agency is not violating contract
- Provider directory does not have level of detail to reflect qualifications
- No accountability for agencies on caregiver quality
- Parents have to track down services and vet – too much weight placed on parent role
- What about applying Division of Quality Assurance (DQA)-certification standards for CLTS providers?
- Opportunities for provider education up front on their service benefit

Technical Assistance

- Anecdotally – families sign ISPs but don't have a lot of provider choices – feel coerced to accept services offered
- How can we bridge gap between available providers and families with a need?
- More materials and info to refer back to beyond the waiver manual
- Provide basic guidelines for employment rules for families (ex: no gift cards)
- Directory specificity is lacking in terms of services, ability to search by certain county
- ex: provider registered as yoga therapist, told families offers massage therapy
- How do providers know what to bill under based on description given?
- Unable to view provider profiles even though Milwaukee is listed on service area in directory
- Could financial management service (FMS) be used for more agencies/counties that lack providers?
- When is the directory going to be updated?
- Gainwell – is there barrier to entering prior authorization if provider did not select MKE? (certain county?)
- Need clarity around ability of providers to offer services statewide (despite listing info)
- Consistency issues from county to county on what is approved service/item
- Sole proprietors – high rates, \$350/hour for certain services
- More training so providers are not saying “what do you need?” to families but instead talking about what they offer

Roundtable Discussion: Working Toward a More Consistent CLTS Experience – Beth Gullickson

Purpose of this conversation: Identify specific examples and ideas that can help the BCS better support consistency while still honoring local strengths and a family-centered approach.

The group started by writing ideas down on post it notes and placing those on the wall under the areas of focus:

1. Access and eligibility
2. Communication and family engagement
3. Service planning and honoring child and family choice
4. Problem solving
5. Other

After this initial activity, the group discussed themes, provided ideas for action items, and discussed areas of priority where investment would make the largest impact.

Summary of themes:

- Serving children under the age of 3
 - The functional screen, which is completed for the purpose of functional eligibility for the CLTS program, does not seem to align with experiences of this age range or feel like it takes a proactive approach.
 - There seems to be confusion from program staff on how to best serve this population once enrolled.
- The functional eligibility process:
 - The screen doesn't capture caregiver capacity or factor that into the algorithm for eligibility.
 - Screeners should receive more training about flexibilities available when conducting the screen to assure the environment the screen is completed in is family friendly. Some individuals noted that it is difficult to talk about their child's deficits in front of them.
 - Screeners would benefit from more assistance in navigating conversations where parents don't agree on accepting services for this child.
- The Medicaid eligibility process:
 - Applying for Medicaid (MA) is very confusing due to many different eligibility pathways, and some families needing to pursue multiple MA programs (e.g. applying for home and community-based waiver, or HCBW, MA while waiting for Katie Beckett MA).
 - Families state it would be helpful if there was just one person to call to help them understand all MA programs, what they are on, and what forms to complete. Families hear from SSCs that they are also confused about the process, and that SSCs are often unhelpful at navigating this process or the multitude of letters they receive.
 - It was noted that counties who have strong relationships with their local Economic Support department may offer a more streamlined and family focused approach to MA eligibility.
- CLTS and the impact of other programs (i.e. CCS and CST) that serve children:
 - Members noted that entry into programs is fragmented across the state based on how local programs are organized and would like to see more streamlining in this area.
 - Families and CWAs struggle with the coordination of benefits component of the CLTS Program. Families feel like they get the run around before CLTS services are authorized and agreed upon.
- General awareness of the program:
 - There have been state level initiatives to enhance awareness, but members discussed that local community outreach, and connections bring forward the best results to assure families don't "fall through the cracks."
- Challenges with MA Card Services and HealthCheck–Other:

- Families experience difficulties accessing benefits that are available through MA card services and under the Health Check Other benefit. Members state that difficult lies with providers being willing to “jump through hoops and mountains of paperwork” for children.
- Children on the CLTS waiver receive fee-for-service (FFS) MA, but then experience delays in receiving needed items, and needing to get items reviewed for medical necessity prior to CLTS coverage.
- Members noted there is still a big gap between how this works in “theory” and what is experienced by families.
- Benefits within the CLTS program seem to be confusing, and the authorization process feels subjective.
 - Outcomes for children seem to overlap without clear alignment with one specific benefit or service category.
 - The lens that SSCs bring can greatly impact the authorization of services. Some families experience judgement and gate keeping, while others are flexible and lean into the process. Member commented that Deciding Together can often feel subjective.
 - Providers need to have the same or similar level of knowledge and expertise to meet child specific needs.
 - Confusion of when Children’s Community Options Program (CCOP) services can or should be utilized, and usage is inconsistent across counties.
- Challenges with solving problems and disagreements
 - Families don’t know where to go next if there is disagreement with the SSC. The appeal process can be hard and time consuming, and creates an argumentative situation, where more communication could move the dial.
 - Issuing notice of actions feel inconsistent, and families may feel like an appeal shouldn’t be necessary if further communication could be had to resolve the situation.
 - Families wanting a state resource to help navigate these situations outside the appeal process. State ombudsman, family training, or state phone line were given as ideas.

After discussion of the above issues, the group discussed priorities in terms of what would promote the greatest positive impact for families in the CLTS Program.

- Members came to agreement that supporting SSCs in the areas of family engagement, program values, youth and family centered planning, communication strategies, and empathy would yield the most positive impact for families enrolled in the CLTS Program.
 - Members articulated that the family experience is defined by the relationship with their SSC.
 - A county’s culture and how they train staff in these areas produce great variability in the way the program is administered as well as how the family experiences the program.
 - Suggestions and examples include producing materials aligned with:
 - Reflective supervision
 - Bias training
 - Shared learning spaces
 - Resources to enhance staff resilience
 - Trainings to enhance empathy, understanding, and communication.
 - Collaboration with other state programs in terms of their trainings in this area and align where possible.

Next meeting dates

- August 6, 2025
- November 5, 2025

MOTION TO ADJOURN: 3:07 pm, Pamela Hencke; SECONDED: Elizabeth Williams

Prepared by: Molly Tull on 5/16/2025.

