

## OPEN MEETING MINUTES

Name of Governmental Body: Children's Long-Term Support (CLTS) Council			Attending: Wendy Heyn, Kelly Blaschko, Anouvong “Toto” Chanthavixay, Anne Dent, Pamela Hencke, Barbara Katz, Michelle Mattox, David McGinley, Angela Milne, Katy Morgan-Davies, Marianne Novella, Cherie Purdy, Tracey Stanislawski, Jamie Willett, Elizabeth (Liz) Williams, Windsor Wrolstad  Excused: Patti Becker, Lisa Hanks, Walt Schalick, Lisa Stephan, Beth Swedeen, Sandra Tierney  Public Members: Vickie Smith, Kristine Serwe, Danielle Tolzmann, Lisa Reindl, Sam Kramer
Date: 8/14/2024	Time Started: 9:00 AM	Time Ended: 12:00 PM	
Location: Virtual Teams Meeting			
Minutes			Presiding Officer: Deb Rathermel

### Welcome:

- Call to Order, Greetings, and Introductions
- Council Members Updates and Announcements
  - New members appointed to the council.
  - Council members shared about a providing a training at the Circles of Life conference called "I could go if I only had a caregiver".
    - Provided a lot of information on providing caregivers and tips and tricks.
    - Will be providing the training at future conferences.
- New Council members
  - Angela Milne
  - Jamie Willett
  - Michelle Mattox
  - Christina Courtney
- Exiting Council Members
  - Barbara Katz
    - Leaving end of August 2024.
- Approve Meeting Minutes from May 8, 2024, Meeting Minutes:
  - Barbara Katz moved to approve.
  - Tracey Stanislawski seconded. Motion passed.

### Public Comments:

- No public comments.

### 2024-27 Budget:

- Next budget will take effect in July 2025 and run through June 2027
- Submitting budget requests includes more than a year long process.
  - Phase of the planning where most items get forwarded from state agencies to the legislature are wrapping up.
- Budget Topics:
  - **CLTS Cost to Continue:**
    - Children's Long-Term Support (CLTS) Program is funded under the Medicaid budget. What the Wisconsin Department of Health Services (DHS) seeks in each budget year is the cost to continue.
    - Budget team makes recommendations for a budget determination.

- Current budget projecting a significant slowing of the rate of enrollment.
- On average over 325 “net new” enrollments into CLTS each month.
- Administration is projecting in the budget that the rate of enrollment will significantly decline to less than 100 kids per month. If the budget were to pass with this projection, CLTS would likely start a waiting list sometime during the next biennium.
  - Data does not support a slowing of enrollment.
  - Statutory entitlement that each eligible child in WI be able to enroll would resolve the budget risk
  - Statutory authority to access would secure continuous enrollment. Council support would be an important catalyst.
  - Other recommendation is supporting the cost to continue at the current rate of enrollment projection.
- Council discussion:
  - A council member stated the council has been advocating for entitlement for CLTS for quite a while. Encourage council to consider supporting this recommendation and communicating with the Secretary.
- **Wisconsin Wayfinder:**
  - Statewide informational referral system. DHS is in a position where new funds will be needed to maintain the current level of resources.
  - Office of Policy Initiatives and Budget (OPIB) is drafting a paper for budget review.
  - Suggest that if the council is interested in this, they recommend to the Secretary that Wisconsin Wayfinder continue in current capacity.
  - A council member asks for a possible bump in funding for Wayfinder to go beyond the referral services. Would be a benefit to provide additional support.
- **Katie Beckett Medicaid:**
  - Increase in resources during the unwinding period. Gap in time where re-eligibility determination was not required. DHS needed to catch up. Individuals went upwards of about 3 years without review. Unwinding function created an uptick in work and additional recourses were provided.
  - DHS is currently meeting the federally required 90-day eligible determination timeline.
  - Current plan, reduce resources to pre-pandemic levels. Projected to result in lag time in the 12-18 months.

#### **Council discussion on 2024-27 Budget:**

- A council member asked if there was a process for community input for state budget prior to determination.
  - Deb Rathermel states that council members could connect with their legislators to share their priorities.
- A council member asked what the timeline is for getting a letter into the secretary.
  - Deb Rathermel states September would be ideal October at the latest.
- Barbara Katz makes a motion to move the chair of the council to write a letter to the DHS Secretary specifying the council’s considerations of the 2024-27 budget to be approved by the executive committee on behalf of the full council to be submitted by November 15.
  - Pamela Henke seconds that motion.
  - A council member requests that the letter is submitted to council members at the same time sent to the secretary.
  - Council chair to follow up with the Bureau of Children’s Services (BCS) for additional information, as needed.
  - A council member asks if there is a draft letter that can be done individually? Recommend when the council writes the letter of support that a signature can be added to one letter, or individual letters can be submitted.
  - A council member asked if the public be able to make comments when the budget is being.

- A council member states individuals can meet with legislative representatives for continued advocacy.
- Next steps: Council chair draft a letter to the secretary. BCS staff is available for technical assistance.

### **In-Person Meeting Follow-Ups – Projects:**

At the May CLTS Council Meeting there was an opportunity to have tabletop discussions to share initiatives and discuss with the Council. Each project will be sharing an update.

- **Early and Periodic Screening, Diagnostic, and Treatment (EPSDT): HealthCheck “Other Services” (HCOS) Project:** Constance Buckner, Bureau of Clinical Policy and Pharmacy

- Goals:

- Pediatric medical necessity – ensuring a wholistic and person-centered approach.
    - Durable medical equipment (DME) – clarify the process.
    - Over-the-counter items (OTC) – clarify the process.
    - Outreach and training – partners across state entities

- Council provided feedback in May. Below are the questions and responses prepared by the bureau of clinical policy and pharmacy:

**DME:**

- There was a request to clarify the HCOS prior authorization (PA) process.
  - The current project has focused on clarification of the PA process for DME and OTC items.
  - All Therapy DME PA reviewers have been trained on the more person-centered, holistic approach to medical necessity needed for HCOS.
  - The PA process has remained the same, and for DME the HCOS reviews occur automatically - there are no additional steps or new steps.
- We received a request for the ability of caregivers/members to contact PA reviewers directly.
  - This is not something we can do. However, the CLTS participants and their families/caregivers have county waiver agency (CWA) staff to assist with understanding PA outcomes. CWAs are a valuable resource.
- A council member requested the need for clear indication of what DME items would be considered restraints and be denied by Wisconsin Medicaid (MA).
  - Wisconsin MA Fee-for-Service (FFS) is currently working on a policy that will outline what devices are considered restraints and ForwardHealth's approach to reviewing items that fall into the restraint category. More information on this topic will be available, hopefully by the end of this year or early 2025.
- A council member suggested DHS create a system to disclose the most cost-effective DME options.
  - This is not something Wisconsin Medicaid can do. It is the DME vendor's responsibility to work with qualified health care professionals (therapists, physicians, etc.) to determine the most medically appropriate equipment for a member and to disclose the most cost-effective option.
- There was also feedback regarding a possible disconnect between outcomes determined at seating clinics and action taken by DME vendors.
  - It would be helpful for us to have this situation fleshed out a bit more. Specific examples would be particularly helpful for a better picture of why this reported disconnect is happening.
    - These details / examples can be reported back to BCS, and the information will be routed to the HCOS Project workgroup.

**OTC items:**

- We received a suggestion for DHS to secure a list of online medical information accessible and unique to pharmacies.
- There were also a couple of comments identifying lack of knowledge regarding the HCOS OTC PA process among many people involved in the process - including: pharmacists, provider services, caregivers/families, etc.
  - The current project has created two flyers that should help increase awareness of OTC coverage.

- These flyers also outline the steps needed if a PA is required.
- We can share these flyers with this council via PDF format as a meeting follow-up.
- The flyers will also be available on DHS HCOS websites.

**General awareness of the HCOS benefit:**

- A council member indicated that increased parent awareness and knowledge of the HCOS benefit would be helpful due to decreased provider awareness.
  - There are online resources available to assist in navigation of the HCOS benefit. Two websites are specifically targeting caregivers and members:
    - [ForwardHealth: The HealthCheck Benefit Helps Children and Young Adults Stay Healthy](#)
    - [ForwardHealth: HealthCheck FAQs](#)
- Council members also wondered how other people are learning about the HCOS benefit:
  - Outreach regarding HCOS is provided in different ways:
    - Providers:
      - Received email alerts and ForwardHealth Updates
      - Participate in meetings with our bureau that occur multiple times per year.
    - County Waiver Agency Staff:
      - Access to DHS websites specific to HC and HCOS
    - School-based partners:
      - Routine communication with the Department of Public Instruction to assist with any information pertinent to school-based services.
  - All partners have:
    - Access to online resources and trainings on DHS websites and on the ForwardHealth Portal.

**Council discussion on EPSDT:**

- A council member is curious about pharmacist education and whether there have been any discussions on reaching out to regional partners for these larger chain pharmacies on training in state specific programs. A lot of families state that the national chain pharmacists are not getting specific direction from their corporations.
  - Current focus on what can be done as a state division and this topic is on the radar to explore.
- **CLTS Family and Participant Handbook:** Tara Sommersberger, Family & Children's Service Coordinator, BCS
  - Result of this project will be a resource for participants and families to learn about the program. Will be available online and will be mailed to families/participants directly.
  - Goal is to create transparency of information to engage with families.
    - Providing the information to empower families.
    - Define and explain expectations of the program.
  - Main takeaways from the family engagement survey:
    - CLTS program supports and services available.
    - Role of the support and service coordinator
    - How much would it cost from parental payment liability.
  - Family Participation collaboration workgroup was created for focused family engagement.
    - Intention of the meetings is to give families and participants the content to review.
    - Receive feedback to continue to develop the handbook with direct perspective from participants families.

**Council discussion on CLTS Family and Participant Handbook:**

- A council member asked how BCS obtained the participation to review the content to the handbook.
  - Participates were provided through partnership with Family Voices.

- A council member asked BCS if this as more user-friendly document or replacement to the waiver manual?
    - The goal is to provide details and information on the program in a more digestible way. Will not replace the waiver manual but the intended audience for the handbook is participants and families.
- **BCS Conference 2024:** Beth Gullickson, Section Manager, BCS
  - Opportunity for program staff to get together in November.
    - Two-day conference, November 5–6.
    - CLTS, Children’s Community Options Program (CCOP), Birth to 3 (B-3), Care4Kids (C4K), and Children with Medical Complexity (CMC) service coordination staff have been invited.
    - Reserved a number of slots for each program to provide an opportunity for representation from each program at this conference. Want every program and agency to be able to send staff.
    - Focus on care coordination/best practice, enhancing professional knowledge of program/policy and understanding the family perspectives.
    - Centralized inbox for questions that are not already addressed during the registration process:
      - dhsbcsconference@dhs.wisconsin.gov

#### **Council discussion on BCS Conference 2024:**

- A council member asked how attendees will fully understand the family perspectives during this conference? How will BCS get that information? Surveys?
    - BCS is currently working on connecting with family voices to provide a family panel. Currently working through the details and will be planning to invite different families to provide discussion.
- **CLTS Transition:** Andrea Warman, Policy Analyst, BCS
  - Moving forward with a project to create a benefit crosswalk from CLTS to adult long-term care (ALTC) programs.
    - Goal to provide more information on services participants could receive in the adult system that are like the services received in CLTS.
- **Third Party Administrator (TPA) Transition:** Tip Pom, Section Manager, BCS
  - Overview: DHS’s fiscal agent (Gainwell) will take over TPA. Anticipated transition is May 2025.
  - Timeline and progress: Initiation and design phase is complete. Project has moved on to construct/test phase. Received feedback from internal and external partners and now construction has initiated.
  - Will continue to have forums with providers to receive additional feedback.
  - 837 electronic process is a newer process for providers, and there are continued demonstrations on this topic.
  - DHS website contains a summary of information that has been shared, claims information, and ForwardHealth Portal user guides and forums and demonstrations in the past and those upcoming.
  - Next steps: will continue to host transition forums in October and December. DHS and Gainwell will announce further training opportunities.

#### **CLTS Program Data:** Dan Kramarz, Section Manager, BCS

- Enrollment and disenrollment
  - Data displays newly enrolled and children that are funded but not yet enrolled and those disenrolled.
  - Enrollment in the program from 2022-2024:
    - Continued increase in enrollment into the program.
    - As of June, 23,170 participants are enrolled. Council can access the information on the CLTS dashboard.
    - Newly enrolled monthly participants range between 300-500 and remains consistent monthly.

- Funded but not yet enrolled are individuals waiting to be enrolled. Right now, there are 1,997 who have met the eligibility criteria and waiting at the county level. (Note: enrollment compliance project is intended to decrease this number)
  - Starting to see a slight downward trend in this number this year.
- Disenrollment data from 2022-2024:
  - As enrollment increases also see disenrollment to increase as well.
  - Top disenrollment reasons, Transition to ALTC, No longer accepting services, suspended, not functionally eligible.
  - June 2023 – May 2024 – disenrollment during unwinding. Largest reason was no longer accepting services, transition to long term care, non-eligible setting, not functionally eligible.
    - No longer accepting services (looking to system change to provide more details) – someone out of contact after multiple attempts at outreach or they chose to disenroll.

#### **Council discussion on CLTS Program Data –Disenrollment:**

- A council member asks if DHS reaches out to for the local practice for some of the partner hospitals.
  - Since the public health emergency (PHE) ended, a policy was added to streamline and provide consistency when it comes to CWAs disenrolling participants due to loss of contact. CWAs are required to connect with the participant through various contacts (phone, email, mail). Does not state contact with collateral contacts (providers/hospitals), but CWAs do need to provide a certain level of contact with families over three months.
    - Policy for denial and termination of program participation due to loss of contact is detailed in Section 2.8.1 of the waiver manual.
  - A council member stated a parent might be unresponsive, but option to work with service coordinator. A lot of calls about rotating service coordinators creates lack of services and frustration.
- Appeals Overviews
  - Definitions:
    - Dismissed – administrative law judge agreed with the decision the county made.
    - Remand – Division of Hearing and Appeals (DHA) agreed with the family.
    - Abandoned- information was sent out to submitter and not returned.
    - Withdrawn – family removed appeal.
    - Interim – waiting for more information.
    - Denied – someone asked for a rehearing and was denied.
- 372 Report Summary
  - Required performance measures that are submitted to the Centers for Medicare & Medicaid Services (CMS).
  - 27 federal performance measures.
  - 23 in compliance
    - 86% at a statewide level of a threshold.
  - 4 in non-compliance
    - Receive a functional screen within 45 days.
    - Participants have providers who meet specific needs.
    - Kids are funded but not yet enrolled within the timeframe.
    - Submitting incident reports.
    - When lower than 86% DHS is required to do some remediation activities.

#### **Council Discussion on 372 Report Summary:**

- A council member asked if data on participants who were denied eligible but found eligible.
    - There is a review process that provides checks and balances to help individuals to not have to go through the appeal process.
- Wisconsin National Core Indicators (NCI) Family Experience Survey:
  - 2023 survey provided broad results.
  - Good opportunity to hear directly from families and hear their experience and where the needs of families are.
  - Response rate is 5.4% and aligns with other surveys.
    - Large survey around 60 questions.
  - Areas of strength in an home and community-based services (HCBS) program:
    - Service delivered in a way that is respectful of family's culture.
  - Areas of lowest result:
    - Not being able to choose care coordinator, family-to-family networks, and alternatives to guardianship.
  - Continued low results in transition and services and supports.

#### **Council discussion on NCI Family Experience Survey:**

- A council member asked if CLTS participants get to choose the county facilitator.
  - Participants can request to change with the county. Generally, there could be variations in processes with the CWA on how they process those types of requests. Families should communicate with the manager of the CWA and talk through concerns about a request for a different Support and Service Coordinator (SSC).
  - A lot of positive comments reviewed on the survey on how SSCs have helped the family. Seen in the comments section. Other council members share they have had SSC change requests granted.

#### **Council member sharing and discussion:**

- A council member shared partners in policy making application is open this week. Parent advocacy makers with lawmakers.
  - [Partners in Policymaking - Wisconsin Board for People with Developmental Disabilities \(wi-bpdd.org\)](https://wi-bpdd.org)
- A council member would like to see some progress on better timeliness when it comes to billing their parental payment liability. Unable to get any information in advance and unable to pay ahead. Should be some sort of timeframe so that it is not such a financial burden on parents.
- A council member shared Wisconsin family leadership institute starting in September in Eau Claire. Value and importance of family input. Topics: imposter syndrome, strategic thinking and more. FamilyVoicesWI.org.
  - [Family Voices of Wisconsin » Wisconsin Family Leadership Institute-WiFLI - Family Voices of Wisconsin \(familyvoiceswi.org\)](https://familyvoiceswi.org)
- A council member is working with helping children with medical disorders that are progressive and terminal. Having difficulty finding resources and is limited. Limitations in Medicaid to get a PCW or a registered nurse based on the severity of the children's medical issues.
  - BCS invites council member to reach out on specific needs or engage with council chair to share specifics to investigate more thoroughly.
- A council member is hearing from other families with children with behavioral issues that it takes a good amount of time before they are offered services through the Comprehensive Community Services (CCS) program. Services are not being offered to children with behavioral diagnosis until much later after enrollment into the CLTS Program.

- An advocacy representative council member shared common themes with working with parents:
  - Case manager turnover leading to concerns with quality of care with children.
  - Often put on parents to be experts on the programs, such as CLTS or HealthCheck. Parents that do not know if services need to be pursued through one program first before another.
  - Calling Disability Rights Wisconsin to explore institutionalization due to county services not being present or difficult to obtain.
  - When is an item considered to be restrictive?
  - Consistently needed to educate parents where they can find CLTS Services at a Glance, the Deciding Together model, and the fair hearing process.
- A council member mentions the deciding together model in connection with complex cases. Parents are also experiencing mental health issues. Providers are not a part of the model. Gaps in the model as the CWA and the parents are working together and providers are not a part of that discussion.
  - A council member states a fundamental problem is that the parent cannot go to the CLTS SSC to ask, “what can we get” and the lack of knowledge of when to use CLTS and the services provided. Hopeful that the handbook will help with the plain language of what is available.
  - A council member provided a resource: Family Voices resource: [Family Voices of Wisconsin » 7. What Services Might be Covered? - Family Voices of Wisconsin \(familyvoiceswi.org\)](https://familyvoiceswi.org/7-what-services-might-be-covered/)
  - A council member mentions it is hard for parents when they receive pushback on services that are recommended but not approved by CLTS, but other families seem to not have difficulty. Have more work to do with consistency.
  - A council member mentions complexity is difficult in the last few years especially with DME since CLTS has been much stricter since 2020. Anything that could be DME needs to have a Medicaid denial. DME will not write those denials because they do not cover the item but then CLTS will not cover. Or HealthCheck other will not cover as well.
  - A council member understands needing to determine the allocation of funds, but sometimes it leads to a lot of work put on parents and it can be exhausting and deterring to continue pursuing resources.
  - A council member feels those parents who can, will purchase out of pocket but shouldn't need to. Recommend keeping this topic around and the complexity of ‘asking’ for needed items.

### Wrap-Up and Action Items:

- 2024 Meeting Dates: November 13, 2024.
- Agenda contains more recent newsletter and CLTS provider bulletin. Recommend review and share with the networks.
- Recently published memo that outlines the requirements for CWAs to timely enroll children into CLTS.
- Draft of the budget paper and draft of the CLTS council's recommendation.
  - Deb Rathermel able to provide technical assistance.

**Motion to adjourn:** Barbara Katz made a motion to adjourn, seconded by Pamela Hencke at 12:00 PM.

Prepared by: Andrea Warman on 8/14/2024.