Katie Beckett Waiver Program Working Group

AGENDA

Monday, December 16, 2024

1:00 PM Zoom Remote Meeting and YouTube Live

I. Convene Meeting
   a. The meeting was called to order by Chair Rep. Jillian Gilchrest.
   b. Members in attendance: Rep. Gilchrest, Sen. Lesser (Co-Chair), Paul Chase (DSS), Molly Cole, Beth Fresa, Emily Germaine-Lee, Dr. Louisa Kalsner, David Negron, Zita Lazzanni, Rep. Moira Rader, Emily Shepard (OFA), Christine Weston (DSS).

II. Remarks by the Chairs
   a. Chair Rep. Gilchrest welcomed the group and asked Sen. Lesser for any remarks. Sen. Lesser welcomed the group, especially at this busy time of year and introduced a new member of the group, Zita.

III. Public Comments – The Chair opened the floor for comments. No comments were made.

IV. Approval of Meeting Minutes – December 2, 2024. The Chair entertained a motion to approve the minutes.

   a. MOTION to approve the minutes of made by Molly Cole, seconded by Sen. Lesser. Motion carried.

V. Further Discussion of Recommendations for Final Report
   a. Waiting List Notification: The Chair invited ideas and suggestions.
      i. Negron mentioned the ideal that the patient/family would know, or could easily check, where they place on the wait list, guidelines of the Program, the types of coverage included, and any restrictions (including financial guidelines). Lesser pointed out the ideal that the waitlist would be eliminated completely.
      ii. Fresa suggested that on a regular basis, at the end of the calendar year or other appropriate date, that families should receive communication regarding their placement on the list, along with a contact person available for clarification. This would be an opportunity to update contact information and confirm continuing interest in the Program.
      iii. Cole mentioned the substantial work the group has done to identify alternative options for this population, and perhaps those alternatives could be made available to those on the waitlist (e.g., TEFRA). Further, she suggested that proper initial/annual screening could assure that this Program is likely to help meet the needs of a particular client/family.
      iv. Rader suggested pursuing additional information for best practices used in other states to reduce the wait list and assure families receive the services they need, and to explore any prioritization criteria for placement on the wait list. Rader emphasized the need to periodically

    reassess the situation with each family to understand if they still benefit by being on the list or if their circumstances have changed.
    v. Kalsner emphasized the need to understand if each person on the waitlist remains in need of the services and perhaps identifying additional clients/families that would benefit from the Program but lack information regarding their options (noting that she first learned about the program from one of her patients).

b. Website/Information for Families: The Chair noted the need for clear publicly available information regarding eligibility for the program, along with alternative options that families might explore.
    i. Range of Services/Alternatives: Cole suggested information about family support groups, diagnosis-specific groups including the Rare Disease Group and places where one might receive help regarding financial assistance or insurance, including Office of Health Care Advocate, Disability Rights of CT, etc. Negron mentioned the necessity to help families explore other waivers or alternative that might be helpful while on the waitlist. Weston (DSS) mentioned the goal for a universal application process to replace the current separate applications for various services. Fresa mentioned the unique features/eligibility for the KB Waiver that sets it apart from other primarily income/resources-based programs. Lesser mentioned the KB Waiver covers a full range of services and perhaps we could consider enhancing certain aspects of care that might be most helpful (e.g., hospital services would be more likely covered by private insurance). He emphasized that we do not lose site of the recommendation to eliminate the waitlist altogether. Fresa suggested an annual update of status, initiated by a letter from DSS and a process for updating all contact information, etc. Cole mentioned home care benefits, pharmacy, medical equipment, or assistive technology might be areas that families max out on insurance coverage. Finding providers is also a challenge.
    ii. Rader: are home modifications covered or are families just considered responsible for the cost? Cole mentioned the Centers for Independent Living that have some limited funds for home modification.
    iii. Fresa: Problems with finding coverage for Home Care is difficult because primary insurance denied care because the level of care was considered “custodial” even though the care required management of trach, suctioning, seizure disorder, whereas Medicaid will cover those services.
    iv. Enhanced/Limited Services: Gilchrest asked a question regarding the potential for enhanced services that might be provided by other states. Ms. Weston explained the details of CT’s plan that waives the parental income criteria in order that the child can have access to Title 19 coverage. Weston commented on the unique features of KB Waiver, partly because the child is considered the “household.” She will follow-up on the possibility of limited services as suggested by Sen. Lesser. Limited services would need to be approved by CMS. Negron advocated for coverage for the full range of services rather than limited services selectively provided. Lesser mentioned that other states reviewed may spend more money on a narrower range of services. Perhaps there are other approaches we have not considered. Lazzarini stressed the

importance of equitable access to services that is ethically defensible, perhaps using quantifiable measures. Rader mentioned some of the challenges of prioritizing care when some clients/families may not even survive the wait time on the list.

   v. Germaine-Lee suggests considering a way to update the client status or change in condition. Gilchrest referred to the discussion above regarding periodic updates to client/family status.
   vi. Age limitations: Fresa mentioned the possibility of clients/families aging out from the KB waiver and being subsumed under other programs after the age of 18. Chase reported that 18–22-year-olds are receiving services within the waiver and mentioned the option of their transitioning to SSI/Husky C. Currently, an age-out report is generated by DSS and a nurse case manager reaches out to families to informally explore options of other coverage; currently, no age limit is mandated, but that could be explored as a recommendation.

c. Next Steps
   i. The report from the Working Group is February 15, 2025. The Chair mentioned a draft document will be generated including the options that have been explored by the Working Group for review and comment by the members; DSS will provide information on the options available within the guidelines for the Program and the estimated associated costs.
   ii. Lesser sought additional feedback from the group regarding the preference for expanding slots or expanding services. Shepard mentioned the potential for exploring other issues such as additional case managers. Lazzarini mentioned ethical principles for making decisions among the options with equity as the guiding principle. Another alternative raised was using other sources for home modifications rather than covering those within the waiver. Cole offered to pull together additional sources for home modification outside the waiver prior to the next meeting.
   iii. The next meeting will focus on review of additional information from DSS and other sources, from which a draft report will be generated for the report.

VI. Announcement of Time and Date of Next Meeting; January 6, 2025, 2-3 PM.

VII. Adjournment: The meeting was adjourned at 2:10 PM

| | |
|---|---|
| Chandra Persaud | Rebecca McClanahan |
| Working Group Administrator | Minutes Prepared by |