Katie Beckett Waiver Program Working Group

MINUTES

Tuesday, February 11, 2025

4:00 PM Zoom Remote Meeting and YouTube Live

I. CONVENE MEETING
   a. The meeting was called to order at 4:00 PM by Chair Rep. Jillian Gilchrest.
   b. Members in attendance: Rep. Gilchrest, Sen. Lesser (Co-Chair), Leslie Bennett, Paul Chase (DSS), Molly Cole, Beth Fresa, Emily Germaine-Lee, Jennifer Handt, M. Mick, David Negron, David Seifel (DSS).

II. REMARKS BY THE CHAIRS
   a. Chair Rep. Gilchrest welcomed the group to the final meeting of the Working Group. She expressed condolences to David Negron for the recent loss of his young daughter while on the wait list and praised his commitment to this work so that other families may benefit. Sen. Lesser expressed his condolences, as well and evoked the inspiration of the Negron family as the work continues to assure that other children and their families benefit from the KB Waiver.

   b. APPROVAL OF MEETING MINUTES – DECEMBER 16, 2024. The Chair entertained a motion to approve the minutes. MOTION to approve the minutes was made by Molly Cole, seconded by Sen. Lesser. Motion carried.

III. CONVERSATION CONCERNING SLOT AND SERVICES DSS
   a. The Chair asked DSS staff for any information or analysis they had that would guide the Work Group in prioritizing recommendations for services covered by the Waiver.
   b. Chase mentioned the chart shared previously regarding average costs per recipient. If detailed information were needed regarding other aspects of the program, the DSS staff would be happy to provide what they can to support the decision-making of the Group.

IV. DISCUSSION ON FINAL RECOMMENDATIONS
   a. RANGE OF SERVICES: Handt mentioned her son does not need hospital services at this time, although they would be very appreciative of & benefit from funds for home modification, as well as behavioral services. Cole cautioned the dilemma of a particular family showing low costs for the Program because the services were not available to them (e.g., home nursing services), and expressed support for changing the age limit at 18, as those clients would then have access to Medicaid without the need for a special waiver as is true for those under age 18. Reassuring families that they are not losing services would be really important. Fresa affirmed that she is a “low cost” recipient because certain services are not available even though they could benefit from services (e.g., skilled nursing services), and having been on the KB Waiver Program provides evidence of a severe disability that would streamline receiving SSDI services as an adult.
   b. AGE ELIGIBILITY: Fresa mentioned the previous discussion of recipients that age-out and supports exploring alternative services for those 18-21 allowing

reallocation of those slots to younger children. Chase mentioned the current age for KB Waiver eligibility is capped at age 22, and as recipients turn age 18 they should be eligible for Medicaid on their own, with very rare exceptions. During the 10+ years of his experience with the Program, there has not been anyone that did not qualify for Medicaid on their own after age 18. If services such as home modification was added and nothing taken away, it could increase costs of the program substantially. Hospital services is by-far the most expensive of services offered. Allowing for a period of transition would be essential, perhaps starting the process at age 17 1/2. Chase mentioned there is a transition process currently in place for 22-year-olds that age out of the Program that could be implemented at a different age if that were changed (the current process of transition is initiated at age 17).

c. Sen. Lesser asked if adults moving off the KB Waiver would lose Nursing Case Management. Chase stated that under Medicaid Husky C for adults with a disability, Intensive Case Management is available if medically necessary (without every 6-month reassessment under the KB Waiver). Cole mentioned there are other places to access Case Management Services, including DDS or PH (if eligible for Title V). The Chair mentioned that is a process that could be explicit on the website for those receiving care under the waiver.

d. Sen. Lesser redirected the conversation to the prior discussion of an annual update process that could be added to the services under the KB Waiver and a more robust public information process so potential recipients can become aware of the options available to them. Chase mentioned that DSS is currently working on “standing up” a web presence for all waiver programs within the DSS, which should not preclude the inclusion of recommendations regarding the website as discussed by the Work Group. Fresa reminded the group that overwhelming challenges of caring for a child with complex medical needs prevents families from tracking critical information about their status on the Wait List – help and guidance is required!

e. The Chair invited input especially from family members regarding other services or information that would be helpful to them. Cole discussed several groups that have good outreach to families and a list of resources could be put together to make available to prospective families. Resources could be disseminated through pediatric units in hospitals and outpatient offices of providers. The Chair asked if the report included a recommendation made to DSS to create a brochure including these resources, would it benefit from the input of the Rare Disease Council? Bennett responded that this work on website landing pages for all of the DSS waivers is on-going and DSS could reach out to the hospital associations, medical associations and the academic health centers in the state with whom they collaborate on these projects. In response to Sen. Lesser’s question, Chase said the websites were expected to live within a few months.

f. Germaine-Lee shared her concern about the lack of effective dissemination of information to providers and then to families that need it most. Perhaps information could be included in DPH Bulletins and as many sources as possible. Negron emphasized the significant resource of a website that includes printable PDFs. Of the 12+ physicians that cared for their daughter, none of them knew about the KB Waiver Program and 1 Occupational Therapist that was aware of the Program assumed it was open to all families. It is worth noting this lack of awareness was within the extensive medical community of New Haven. The Negron family learned about the program through a national conference regarding Tay Sachs disease. Because many of these client’s eventually seek care from a Geneticist, the information should be disseminated in those practices, as well and it is important to assure this is available to all families regardless of income since KB Waiver is the only non-income-based program of its type. Negron emphasized the immense challenges for families struggling to manage their complicated lives while caring for a high-needs child.

g. Handt encouraged the inclusion of Nurses because of their essential role in communicating with families. Cole reinforced the need for providers other than physicians to be aware of the program, as referrals for services may be made by Social Workers, Child Life Specialists, Nurses, or others, so targeting of children's hospitals should help with all these providers.
h. Mick mentioned that providers received Medicaid updates through the HP system of payment and suggested dissemination of information through that system as a way to communicate with all providers paid through that system. In response to a question from Mick, Chase commented on the "no wrong door" mechanism to assure that a person seeking help can find their way by accessing any source of information from DSS and is supported by using a universal assessment tool for all Medicaid waiver programs, in addition to the enhanced websites/landing pages for all programs.
i. The Chair summarized the report from the Work Group that will be drafted by the CGA team. The report will summarize the processes of the group and presentations received, as well as the recommendations made. The recommendations will include wait list notification, website/information for families, wide dissemination of information, reduce the age of eligibility to 18, and decrease and eventually eliminate the waiting list. Fresa stated a personal priority of having more children ON THE LIST and receiving services rather than expanding the services that are available. Bennett agreed with the priority stated of having more people covered rather than more services made available, if that is the choice to be made; she shared that having nursing services alone has made it possible for her to care for her child in her own home even though they could benefit from a broader range of services. Handt is aware of the state of MN where the wait list is very minimal, and a full spectrum of services is available, including home modifications, and recommended that approach be a model for the state of CT. A member of the group stated the preference that no recommendations would be made regarding prioritization by severity of condition or other qualitative indicators of need.
j. Sen. Lesser proposed that we articulate a plan for a multiple-year process of eliminating the wait list and expanding services similar to other states. Seifel affirmed DSS receptivity to collaborating on such a plan. Lesser commented that we do have the opportunity to recommend such a process, knowing it would require future commitments from CGA, DSS, and others.
k. Germaine-Lee asked if there were services that were not used frequently that could be removed or adjusted. The Chair clarified that when one is approved under the KB Waiver, they qualify for Medicaid and includes whatever services are offered under the state plan within Medicaid. Chase affirmed that perception and clarified that one must qualify for at least one additional service for the KB Waiver and Case Management Services are that one thing, and further, predicting which services will be accessed with the waiver is unique to individuals and varies widely year to year providing little guidance for selecting among the services.
l. Handt clarified why she feels home modifications are so important, especially when a covered person's condition/function deteriorates quickly. The Chair

summarized that these services could be planned as a phase-in, along with other recommendations. Mick mentioned the possibility of modeling home modification services under the KB Waiver on other waivers (i.e., brain injury waiver).

m. NEXT STEPS: members of the Committee will receive a draft of the report, and are asked to give feedback as soon as they are able. There will have a tight turnaround for the final report that will be shared with all Committee members and with the entire Legislature. The report will become the basis for moving forward with legislative action or specific tasks for DSS. Of course, the elimination of the wait list and the enhancement of the services covered would be the ultimate goal.
n. Handt asked about the impact on CT Medicaid program of dramatic changes at the federal level. Sen Lesser commented about the current circumstances and the resulting uncertainty. The Chair encouraged members of the Working Group to reach out at any time with comments or suggestions on the KB waivers or any other ideas for improving the system.
o. The Chair and the Senator expressed their appreciation for the good work accomplished by the Working Group.

V. ADJOURNMENT: the meeting was adjourned at 5:04 PM.

Breanne Clifton — Rebecca McClanahan

Working Group Administrator — Minutes Prepared by