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Commissioner Lisa Lee
Department for Medicaid Services (DMS)
Division of Long-Term Care Services and Supports
275 East Main Street 6W-B
Frankfort, Kentucky 40621
Via email: MedicaidPublicComment@ky.gov

Re: Public Comment for Proposed Addition to Kentucky's 1915(c) Home and
Community Based Services (HCBS) Waiver: Kentucky Community Health
for Improved Lives and Development (CHILD) Waiver

Dear Commissioner Lee:

The Commonwealth Office of the Ombudsman (COO) applauds the General Assembly's move to establish a Section 1915(c) Home and Community Based Services (HCBS) waiver dedicated to children with high-intensity needs, including severe emotional disabilities (SED), autism spectrum disorder (ASD), and intellectual disabilities and related conditions (ID/RD).

The COO has reviewed the proposed CHILD waiver form and offers public comments on it. Pursuant to KRS 43.035, the COO shall make recommendations to improve the performance of and resolve complaints about the Cabinet for Health and Family Services (CHFS) and provide evaluation and information analysis of CHFS's performance and compliance with state and federal law. The COO receives a number of complaints about the backlog for waiver services available to Kentuckians and has eagerly awaited the unveiling of the Child Specific Waiver.

Target Group Specification (1). House Bill (HB) 6 (2024) appropriated money to CHFS "to develop a HCBS Section 1915(c) waiver for children ages 0-21 with severe emotional disabilities, autism spectrum disorder, and intellectual disabilities and related conditions." Appendix B of the CHILD waiver form specifies the target group of individuals who are served by the waiver and the number of participants the state expects to serve during each year the waiver is in effect. It provides for those mentioned in HB 6, but then adds four additional criteria, one of which must be met for the child to be eligible. These include: (1) the child has no stable housing or is in serious risk of losing his or her housing because of the child's disability; (2) the child is in foster care and has been moved at least twice in the past year due to the child's disability; (3) the child has had at least

five interactions with law enforcement in the previous year as a result of the child's disability; or (4) the child will be released from a treatment facility within 45 days and needs support at home offered by the CHILD waiver.

Those outlined additional criteria are incredibly limiting. As you know, the COO received numerous complaints regarding HCB youth reassessment denials between January and May 2025. Many parents of these children expressed hope that the new CHILD waiver would help many of those children who were denied HCB level of care during their reassessment. The limiting criteria appear to extend far beyond what was envisioned in HB 6 and will exclude those recently removed from the HCB Waiver.

As of June 23, 2025, there are 4,925 individuals on the HCB Waiver waitlist, of which 725 individuals are between the ages of 0-21. Furthermore, there are 9,513 individuals on the Michelle P. Waiver waitlist, and 7,388 of those individuals are between the ages of 0-21. With such a significant number of Kentuckians languishing on a waiver waitlist, what was the rationale to limit the population of individuals eligible for the CHILD waiver?

Early intervention is critical. Even if CHFS focused on kids aged five and under on both of the respective waiver waitlists referenced, the number would exceed 1,000 Kentuckians. These are Kentuckians desperate to help their families. The eligibility restriction significantly undermines the priorities established by the General Assembly when it enacted HB 6 during the 2024 Regular Session.

Target Group Specification (2). Under Appendix B-3, the waiver application limits the number of unduplicated participants to 100 per year. Because one of the criteria is foster-care placements, there is a concern that CHFS will fill up this waiver program with children in care and exclude other members of public altogether. Are there any guarantees that won't happen?

Target Group Specification (3). It is currently reported that there are over 9,000 people on the waiting list to receive the Michelle P. Waiver. Will individuals on the waiting list be eligible to apply for this waiver, and will they receive priority consideration? Also, to receive services under the CHILD waiver, the applicant, under Appendix B-1, must have "exhausted other services and supports." The CHILD waiver application does not define "exhausted." Please define exhausted. Would those who are on the Michelle P. Waiver waitlist meet the definition of exhausted?

Participant Appeal Rights. Under Appendix F, the CHILD waiver application provides that the "Office of the Ombudsman" is an "entit[y] authorized to assist participants with filing an administrative hearing request." On July 1, 2024, the COO was removed from CHFS and relocated under the Auditor of Public Accounts. Since the COO was removed from CHFS, DMS has refused to use the COO to process Medicaid hearing requests, even though other agencies within CHFS continue to do so. Will DMS use the COO to allow participants to file an appeal? It is unclear if this was an oversight by the drafter of the application or CHFS's intention, since the COO has not received any communication from DMS about processing CHILD waiver hearing requests. The COO has previously requested that the CHFS Secretary set up a meeting with the Commissioner of DMS, but CHFS has not responded to those attempts.

Participant Direction of Services. Under Appendix E, the CHILD waiver does not provide for participant direction of services. More specifically, Appendix E notes that services offered under the CHILD waiver are only provided by qualified, certified Medicaid-enrolled providers. Relatives, parents of minor children, foster-care parents, or guardians would be prohibited from providing services under this waiver.

Participant direction of services empowers families to take the lead in finding, selecting, and managing waiver services that best meet their child's needs. Participant direction of services also aligns with the waiver's person-centered philosophy. It gives participants and their families real decision-making authority over who provides services and how the waiver funds are spent.

Under CHFS's plan though, it appears that participant families cannot choose who they want for non-medical waiver services. Indeed, CHFS's failure to provide for participant direction of services runs counter to the Centers for Medicare and Medicaid Services' (CMS) express wishes: "CMS urges states to afford all waiver participants the opportunity to direct their services." It is also contrary to the views of the focus group participants of CHFS's Children's Waiver Feasibility Study. On page five of that study is the following in bold font: "Participant Directed Services are considered essential and allow for much needed care for a child with SED, ID/RC, and ASD. Focus group participants strongly advocate for legally responsible individuals to serve as self-directed employees." Was the Children's Waiver feasibility study released by CHFS utilized when deciding not to include participation direction of services? Will CHFS ensure that CHILD waiver families have the option to choose a provider that they want?

Allocation of Funds. Under Appendix J, the total estimated cost of the CHILD waiver for Year 1 is \$14,035,804. Of that total, 68% (\$9,487,500) is estimated to go toward supervised residential care. This percentage remains constant for each of the five years in Appendix J. This, combined with the very limiting criteria in Appendix B and the lack of participant direction of services in Appendix E, gives the appearance that the CHILD waiver funds will be instantly filled with children already in CHFS custody, never allowing the general public to use the waiver.

We ask CHFS to publicly guarantee that CHILD waiver funds will be made available to eligible children in the community—rather than being automatically consumed by those already in CHFS custody. Please outline the procedures you will implement to prioritize new enrollees, monitor enrollment trends, and report regularly on fund allocation to ensure transparency.

Thank you for taking the time to consider the COO's comments. I look forward to hearing your responses.

Best regards,



Jonathan Grate, Ombudsman
Commonwealth Office of the Ombudsman