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MEMORANDUM

To: Robert Stivers, President of the Senate
David Osborne, Speaker of the House
Members of the Legislative Research Commission

From: Senator Julie Raque Adams, Co-chair
Representative Steve Riley, Co-chair
1915(c) Home and Community Based Services Waiver Redesign Task Force

Subject: Findings and Recommendations of the 1915(c) Home and Community Based Services Waiver Redesign Task Force

Date: December 15, 2021

In a memorandum dated May 26, 2021, the Legislative Research Commission (LRC) established the 1915(c) Home and Community Based Services Waiver Redesign Task Force. The task force was established to review previous waiver redesign efforts undertaken by the Cabinet for Health and Family Services (CHFS) and to develop recommendations to ensure the quality and stability of the 1915(c) waiver services in Kentucky.

The eight-member task force began meeting in June 2020 and convened six times during the 2021 Interim. The task force heard testimony from more than two dozen individuals, state agencies, advocacy groups, and 1915(c) waiver service recipients and their family members on various topics including the availability of waiver services, reimbursement rates for waiver services, waiver waiting lists, direct support professional (DSP) and waiver provider workforce shortages, and administrative regulations related to provision of waiver services.

In accordance with the May 26, 2021, memorandum, the task force submits the following findings and recommendations to LRC for consideration. These findings and recommendations

are based on the testimony provided to the task force during the 2021 Interim. This memorandum serves as the final work product of the task force.

Findings

1. **Kentucky currently operates six 1915(c) Home and Community-Based Services (HCBS) waivers to provide care, services, and supports to approximately 26,000 individuals with disabilities. The alternative to providing these services in the home or community is institutionalized care.**

   Federal law permits states the option to develop 1915(c) HCBS waivers to meet the needs of individuals who prefer to receive long-term care, services, and supports in their home or community, rather than in an institutionalized setting. Nearly every state and the District of Columbia offer HCBS waivers to more than one million individuals with a diagnosed physical, mental, intellectual, or developmental disability, and there are currently more than 300 active HCBS waiver programs nationwide.

   Kentucky has received federal approval for six 1915(c) HCBS waivers. These are the Acquired Brain Injury (ABI) and Acquired Brain Injury Long Term Care (ABI LTC) waivers for individuals age 18 or older with an acquired brain injury; the Home and Community Based (HCB) waiver for individuals age 65 and older or individuals or any age with physical disabilities; the Model II waiver for individuals who are dependent on a ventilator for 12 or more hours per day or who are on an active, physician monitored ventilator weaning program; and the Michelle P. waiver and the Supports for Community Living (SCL) waiver for individuals with intellectual and developmental disabilities. Through these six waivers, in state fiscal year 2019 the Department for Medicaid Services (DMS), provided more than $940 million in care, services, and supports to 26,383 Kentuckians with physical, intellectual, or developmental disabilities in their home or community. Without flexibility and the services offered through 1915(c) HCBS waivers, many of these individuals would have had no choice but to receive needed care, services, and supports in an institutionalize setting such as skilled nursing facilities, intermediate care facilities for people with intellectual disabilities, and inpatient psychiatric hospitals.

2. **Providing needed services in a home or community-based setting is more cost-effective than providing similar care in an institutionalized setting, but Kentucky spends significantly less than the national average on home and community-based services. A 10 percent increase in the federal medical assistance percentage (FMAP) for HCBS through March 2022 will result in approximately $499 million in additional federal funding for Kentucky's waiver services.**

   Federal guidelines from the Centers for Medicare and Medicaid Services require that 1915(c) HCBS waivers be budget neutral. This means that states must demonstrate that the cost of providing care, services, and supports in the home or community is equal to or less than the cost of institutionalized care. The current aggregate cost for providing services to individuals with a disability in an institutionalized setting in Kentucky is $29,306 per person, per month. In state fiscal year 2019, the average total of paid claims across all six HCBS waivers in Kentucky was $5,218 per person, per month and ranged from a high of $8,429 per person,

per month in the ABI LTC waiver to a low of $1,245 per person, per month in the HCB waiver.

When compared to other states, Kentucky's spending on HCBS waivers is well below the national average. Home and community-based services spending falls into the larger expenditure category of long-term services and supports (LTSS). Nationally, HCBS waivers accounts for roughly 56 percent of LTSS spending, but in Kentucky HCBS spending accounts for just 42.8 percent of the state's total LTSS expenditures. This places Kentucky in the bottom quartile of states, and the national average for spending on HCBS is $298.18 per resident. Kentucky spends just $200.21 per resident on HCBS, or nearly one third less than the national average.
The American Rescue Plan Act included a 10% percent FMAP increase for expenditures related to the delivery of 1915(c) waiver services between April 1, 2021, and March 31, 2022. CHFS estimates that this 10% percent FMAP increase will result in approximately $499 million in additional federal funds for the state. Under federal law, these enhanced FMAP funds may be used only to strengthen and improve the delivery of 1915(c) waiver services.

3. **More than 10,000 eligible Kentuckians with an intellectual or developmental disability are waiting for waiver services. Two of Kentucky's six 1915(c) waivers, the Michelle P waiver and the Supports for Community Living waiver, have extensive, multi-year waitlists.**

   More than 7,500 eligible Kentuckians are on a waitlist for the Michelle P. waiver with an average of 78 additional individuals being added to that waitlist each month. According to CHFS, DMS is currently processing applications dating back to 2015. This means that if a Michelle P. waiver slot were allocated to an individual today, that individual most likely waited six years for those services.

   For the SCL waiver, the waitlist includes nearly 3,000 eligible individuals, and on average, 30 additional individuals are added to the SCL waitlist each month. Individuals on the SCL waitlist are categorized as either "urgent" or "future planning." Of the nearly 3,000 individuals waiting for SCL waiver services, 119 are in urgent need of services. While there are fewer individuals on the SCL waitlist than the Michelle P. waiver waitlist, the wait can be three or four times as long.

4. **There is a well-documented direct support professional and 1915(c) waiver workforce crisis. Low funding for wages combined with the emotionally demanding nature of supporting and caring for individuals with a disability has made recruitment and retention of a qualified workforce nearly impossible for waiver service providers.**

   A burgeoning workforce crisis is negatively affecting both 1915(c) waiver service providers and the individuals who receive those services. Service providers are currently operating at critically low staffing levels, are experiencing significantly increased overtime costs, and are facing reduced revenue all while providing vitally necessary care to some of Kentucky's most vulnerable citizens. This workforce crisis also affects individuals' ability to access

much needed care, services, and supports. Many service providers have reported having to turn down referrals, despite having capacity, due to their inability to recruit and retain adequate staff. Individuals who choose to self-direct services through the participant directed services program face extreme difficulty in hiring and retaining DSPs.

One of the most prominent contributors to the DSP and 1915(c) waiver workforce crisis is wages. Wages in this sector remain extremely low and have not kept up with inflation as some waivers have not received a rate increase in nearly 20 years. Because waiver services are entirely funded by Medicaid, providers cannot raise wages without a corresponding reimbursement rate increase. Kentucky's HCBS waiver reimbursements support an average hourly wage of between $10 and $12; these wages are not competitive with an increasing number of retailers, distribution warehouses, and fast food restaurants offering to pay wages of between $15 and $20 per hour.

5. **Overly burdensome administrative regulations impact the efficiency of service delivery and often create unfunded mandates for service providers.**

   Administrative regulations promulgated by the CHFS and its subsidiary departments require significant documentation and create tremendous administrative burdens for service providers. Compliance with these regulatory requirements is mandatory, but service providers are not reimbursed for tasks or duties required by regulation. Stakeholders identified several regulatory requirements that increase the cost of service delivery and decrease efficiency, including regulations governing the referral process that can deter providers from agreeing to support individuals with high-intensity needs, regulations governing the involuntary termination of services that require providers to continue to support individuals even when the needs of the individual exceed the level of support the provider can delivery, and regulations requiring regular person-centered team meetings that generally must be conducted in-person requiring staff travel without reimbursement.

6. **The policy recommendations put forth by the 2020 Exceptional Support Waiver Services Task Force have not been implemented. The findings and recommendations of this previous task force are still valid and have been reaffirmed by the work of this task force.**

   During the 2020 Interim, LRC established the Exceptional Support Waiver Services Task Force to study and make recommendations regarding 1) new exceptional support services and payment models that will allow waiver service providers to provide the level of care necessary to support high-intensity individuals; 2) creating efficiencies within the Cabinet for Health and Family Services to ensure that participants receive high-quality exceptional supports when they are needed without delay or interruption; 3) creating efficiencies within the Cabinet for Health and Family Services that support quality care and outcomes; 4) which critical outcomes can be measured and used to improve the exceptional support service model; and 5) how federal, state, and local resources are being used to optimize these outcomes and how resources can be better coordinated or redirected to meet the needs of high-intensity waiver participants in the state. To date, the recommendations of the Exceptional Support Waiver Services Task Force, submitted to the LRC in a findings and

recommendations memorandum dated November 23, 2020, have not been implemented. The work of this task force has reaffirmed many of the findings and recommendations contained in the previous task force's findings and recommendations memorandum.

Recommendations

The task force recommends that the Kentucky General Assembly take the following actions during the 2022 Regular Session:

1. Prioritize implementation of the recommendations of the 2020 Exceptional Support Waiver Services Task Force as presented to LRC in a memorandum dated November 23, 2020.

2. In the 2022-2024 Biennial Budget bill, appropriate sufficient funds to accomplish the following:
   a. Maintain current funding levels for SCL Residential Level 1 and ABI Residential services by making permanent the 50 percent rate increase authorized under Kentucky's Appendix K emergency preparedness and response amendments, without day service attendance exclusions, after the expiration of Appendix K;
   b. Implement a 25 percent increase to reimbursement rates for all 1915(c) waiver services with the exception of SCL Residential Level 1 and ABI Residential services; and
   c. Increase DSP wages.

   This appropriation may be appropriated from either general fund dollars or from the nearly $500 million in enhanced FMAP funds that Kentucky expects to receive from the federal government and should use a phased-in approach with $41,550,465.50 being appropriated in the first year of the budget and an additional $83,100,931 being appropriated in the second year.

3. Enact legislation similar to House Bill 564, which vetoed by the Governor during the 2020 Regular Session, to establish a definition of "attendant care" and to require that attendant care be an available service in all 1915(c) waivers.

4. Enact legislation to establish crisis residential services within the SCL waiver and appropriate sufficient funds for these services.

5. Enact legislation to establish an SCL waiver service for participants with long-term support needs while also retaining an overhauled exceptional support system. Such legislation should, at a minimum
   a. establish criteria for individuals whose support needs are greater than what can be provided in SCL Residential Levels 1 and 2;
   b. establish long-term crisis services for SCL waiver participants; and
   c. retain the current exceptional supports system to be used exclusively for short-term crisis stabilization and transition.
6. Enact legislation directing CHFS to assist waiver service providers with the costs associated with onboarding employees, including required background checks and drug screenings.

7. Include language in the 2022-2024 Biennial Budget bill directing CHFS to coordinate with relevant stakeholders to implement the following:

a. Regular cost of living adjustments for all waiver service reimbursement rates,
b. Regular wage analysis, and
c. Funding to support a robust and qualified workforce and true person-centered care.

8. Direct CHFS to prepare and submit a Medicaid waiver application to establish a Serious Mental Illness waiver that includes at least the following services:
   a. Supported housing;
   b. Medical respite care; and
   c. Supported employment.

9. Direct CHFS to study SCL exceptional supports and the potential impacts of long-term crisis transition services and require the cabinet to provide its results to the Interim Joint Committee on Health, Welfare, and Family Services no later than November 30, 2022.

10. Direct CHFS to offer a training program for individuals and families who use self-directed services. Such a training program should include
    a. training on the duties and responsibilities of self-directed services,
    b. training on relevant employment laws, and
    c. training on proper documentation.

11. Direct CHFS to study the impact and effectiveness of the Family Home Provider service in the ABI and ABI LTC waivers and require the cabinet to provide its results to the Interim Joint Committee on Health, Welfare, and Family Services no later than November 30, 2022.

12. Direct CHFS to ensure continued access to cognitive rehabilitative services and continuity of care for those living with brain and spinal cord injuries and to expand the ABI and ABI LTC waivers to include
    a. medically complex and neurobehaviorally challenged individuals,
    b. specialized behavioral health services, and
    c. risk-adjusted rates for services.

13. Direct CHFS to seek federal approval to maintain all Appendix K amendments and flexibilities provided throughout the COVID-19 pandemic to ensure that waiver services providers have the ability to adequately address individuals' evolving needs in a post-pandemic environment.

14. Direct CHFS to develop a strategy to significantly reduce or eliminate the Michelle P. waiver and SCL waiver waitlist and require the cabinet to present this strategy to the Interim Joint Committee on Health, Welfare, and Family Services no later than November 30, 2022.

15. Direct CHFS to develop a plan for transitional services and to maintain continuity of care as individuals move from one waiver to another, particularly when waivers have waiting lists for new enrollees.

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