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**Before the Committee on Health
Council of the District of Columbia**

Performance Oversight Hearing Regarding the Department of Health Care Finance

March 4, 2021

The Legal Aid Society of the District of Columbia¹ submits the following testimony regarding the Department of Health Care Finance’s (DHCF) administration of the Home and Community-Based Waiver Program for the Elderly and Physically Disabled (EPD Waiver), and in particular, the provision of Personal Care Aide (PCA) services to EPD Waiver beneficiaries.

EPD Waiver services allow Medicaid beneficiaries who might otherwise need to live in nursing home facilities to remain at home, living in the community. Waiver services include but are not limited to PCA services, case management services, homemaker services, and adult day health services. PCA services allow D.C. residents to safely complete routine daily activities – such as using the toilet, getting around inside their homes, managing their medication, preparing food, and getting dressed – when it would otherwise be dangerous for them to attempt to do so alone.

Based on our representation of and other interactions with individuals receiving or applying for these services, Legal Aid is concerned that the assessment tool used to determine non-financial eligibility for the EPD waiver program does not adequately capture the medical needs of D.C. residents. We are also concerned about the implementation of a cap on PCA services for all EPD waiver beneficiaries at 16 hours per day once the COVID-19 public health emergency (PHE) ends.

¹ The Legal Aid Society of the District of Columbia was formed in 1932 to “provide legal aid and counsel to indigent persons in civil law matters and to encourage measures by which the law may better protect and serve their needs.” Legal Aid is the oldest and largest general civil legal services program in the District of Columbia. Over the last 89 years, Legal Aid staff and volunteers have been making justice real – in individual and systemic ways – for tens of thousands of persons living in poverty in the District. The largest part of our work is comprised of individual representation in housing, domestic violence/family, public benefits, and consumer law. We also work on immigration law matters and help individuals with the collateral consequences of their involvement with the criminal justice system. From the experiences of our clients, we identify opportunities for court and law reform, public policy advocacy, and systemic litigation. More information about Legal Aid can be obtained from our website, www.LegalAidDC.org, and our blog, www.MakingJusticeReal.org.

The InterRAI Assessment Tool Does Not Adequately Capture the Medical Needs of Beneficiaries

The InterRAI assessment tool is a standardized, face-to-face assessment used to determine eligibility for the EPD Waiver. The District contracts with Liberty Healthcare Corporation who provides Registered Nurse (RN) assessors to administer the assessment tool. After the District began using this InterRAI assessment in 2018, Legal Aid and other service providers saw a large increase in the number of Medicaid beneficiaries whose PCA services were drastically reduced, or in some cases, terminated altogether. Although we appreciate DHCF's willingness to engage with stakeholders about the EPD Waiver program and have had multiple clients whose PCA services hours have been restored or increased upon reassessment, we remain concerned that the InterRAI assessment tool is not adequately capturing the medical needs of EPD Waiver beneficiaries, including the over 1,000 District residents whose waiver services were terminated or reduced in FY18.²

The InterRAI assessment results in a total numerical score made up of three separate scores pertaining to a person's functional, cognitive/behavioral, and skilled care needs.³ People with a total assessment score of at least 9 qualify for the EPD Waiver. The functional part of the assessment evaluates the type and frequency of assistance the person requires for various activities of daily living (ADLs) and instrumental activities of daily living (IADLs).⁴ For each activity, the assessor selects which of the following assistance is needed for the person to complete the activity: Independent, Setup Help Only, Supervision, Limited Assistance, Extensive Assistance, Maximal Assistance, or Total Dependence. Each of these options has a corresponding score and range of PCA service hours associated with that score. A person's PCA service hours are determined only by the scores related to assistance needed to complete the following ADLs: bathing, transferring, dressing, eating/feeding oneself, toileting, and maintaining bowel and bladder control.⁵ IADLs, which do not factor into the PCA service hour determination, include meal preparation, housework, shopping, and transportation.

Since the InterRAI assessment tool was first implemented, Legal Aid has seen inconsistent and concerning results. Clients who had been receiving a substantial number of hours of PCA services for years saw extreme reductions without any corresponding change in their conditions. For example, a client was receiving 14 hours of PCA services each day at the time of his 2018 assessment. His need for assistance with ADLs is based on mental health conditions. According to his caregiver, without assistance, he gets out of the shower before rinsing off the soap, does not dress himself appropriately, does not eat appropriate meals, gets lost walking around, and sometimes needs to be reminded to clean himself after using the toilet. His 2018 annual assessment resulted in his PCA services being reduced to 4 hours each day. His 2019 assessment

² DHCF FY19-FY19 Oversight Responses, Q56 and Q57.

³ *Id.*

⁴ *Id.*

⁵ 29 DCMR 5099.1.

resulted in approval for 9 hours of PCA services each day, and his 2020 assessment resulted in approval for 7 hours of PCA services each day. Legal Aid observed his 2019 and 2020 assessments, and both times the RN assessors acknowledged that the InterRAI assessment would not adequately capture the number of PCA services he needs because he is physically able to independently complete his ADLs.

Although District regulations provide that one goal of PCA services is to “provide cueing,⁶ hands-on assistance, and safety monitoring related to activities of daily living to beneficiaries who are unable to perform one or more activities of daily living,”⁷ the assessment tool is only designed to assess the need for hands-on assistance. It fails to fully capture the cueing and safety monitoring needs of people who may not need hands-on assistance but are still unable to independently complete their ADLs due to mental and/or cognitive conditions. We have seen multiple clients like the one described above who, due to dementia or a mental health condition, need almost constant cueing and safety monitoring, but whose PCA services were drastically reduced due to the limitations of the InterRAI assessment itself.

Further, in discussing the assessment tool with DHCF and other service providers, Legal Aid learned that the RN assessors do not have the discretion to adjust the functional score if they observe medical needs that are not captured by the tool itself. For example, as currently administered, the assessment tool has a “look-back period” of three days even though regulations require a look-back period of seven days.⁸ This means that when assessing ADLs, the RN assessor is only supposed to score the assistance needed in the three days prior to the assessment. If the person assessed needs extensive assistance with an activity of daily living in the three days prior to the assessment, but maximal assistance with that same activity just outside the three days, the RN must select that only extensive assistance is needed for that activity. There is no mechanism for the RN assessor to recommend the need for a higher level of assistance if that need is not adequately captured by the tool itself. Again, this remains true even if the assessor disagrees with the final assessment score and believes that the person clearly needs more help.

The Cap on PCA Services for EPD Waiver Beneficiaries Will Place the Most Vulnerable Enrollees at Serious Risk of Harm or Institutionalization

Legal Aid is also concerned about the implementation of a cap on PCA services once the COVID PHE ends.⁹ Effective October 1, 2020, the Centers for Medicare & Medicaid Services (CMS) approved the District’s proposed EPD Waiver Amendment, which included limiting PCA

⁶ Cueing is defined in 29 DCMR 5099.1 as “using verbal prompts in the form of instructions or reminders to assist persons with activities of daily living and instrumental activities of daily living.”

⁷ 29 DCMR 5000.2.

⁸ 29 DCMR 989.11.

⁹ <https://dhcf.dc.gov/epd-waiver-amendment>

services to 16 hours per day.¹⁰ While Legal Aid appreciates the steps DHCF has taken to delay implementing this change during the PHE, we are concerned that once this change does take effect, it will place these vulnerable community members at serious risk of harm or institutionalization because it is still unclear that other waiver services provide viable alternatives for care.

Legal Aid has represented multiple individuals who require 24 hours per day of PCA services in order to safely complete their ADLs and avoid institutionalization. These individuals have needed 24 hours of care for conditions such as dementia and a danger of wandering, paralysis resulting in the use of urine and colostomy bags that need to be changed every three hours to avoid infection, and limited mobility combined with incontinence that limits their ability to go to the bathroom, clean themselves up, or change their adult diaper on their own without risk of falling.

As written, the EPD Waiver amendment limits PCA services to 16 hours per day with *no exceptions* based on medical need.¹¹ DHCF is required to provide services to individuals in the “least-restrictive setting,” and in such a way as to not create a serious risk of institutionalization.¹² Legal Aid is concerned that this type of inflexible cap will make it more likely that beneficiaries who are currently (or who would, except for the cap, in the future be) approved for 17 to 24 hours of PCA services per day would need to be institutionalized to get medically necessary assistance with activities of daily living.

There is a Lack of Evidence Demonstrating that the Medical Needs of
Beneficiaries Currently Receiving 17 to 24 Hours Will Be Met By Other EPD
Waiver Services Once the Cap is Implemented

In the proposed amendment, DHCF stated that any reduction in PCA hours to EPD Waiver participants receiving between 17 and 24 hours of PCA services per day will be offset by the inclusion of appropriate alternative services in the participant’s person-centered plan, *e.g.* Adult Day Health Programs, Personal Emergency Response System, homemaker services, and chore aide services.¹³ However, Legal Aid is still concerned that these alternative services will not be able to provide medically necessary assistance with completion of ADLs for all those who would be affected by the proposed cap. Our specific concerns include the following:

¹⁰ <https://dhcf.dc.gov/epd-waiver-amendment>

¹¹ *Id.*

¹² *Olmstead v. L.C. by Zimring*, 527 U.S. 581 (1999).

¹³ Application for 1915(c) HCBS Waiver: Draft DC.003.04.08 – April 04, 2020, p. 16 (https://dhcf.dc.gov/sites/default/files/dc/sites/dhcf/page_content/attachments/EPD-Waiver-Amendment-April-2020.pdf).

1. **Adult Day Health Program Services:** It seems that DHCF is expecting these services to make up a substantial portion of the care for people who currently receive more than 16 hours per day of PCA services. However, it is unclear whether the District's Adult Day Health Programs have the capacity or the capability to meet the needs of beneficiaries that would be affected by the cap, *i.e.*, those who require constant or near-constant monitoring and assistance, such as people with advanced dementia or those experiencing paralysis.
2. **Homemaker and Chore Aide Services:** Homemaker services consist of general household activities, *e.g.* food preparation and routine household care, provided by a trained homemaker when someone is unable to manage the home and/or care for themselves or others in the home.¹⁴ Chore aide services consist of heavy household chores to maintain the home in a clean, sanitary, and safe environment, *e.g.* washing floors or moving heavy furniture to provide for safe entry and exit.¹⁵ Neither service is meant to provide assistance with completing ADLs, and it is unclear how DHCF contemplates they will make up for the loss of PCA services caused by the cap.
3. **Personal Emergency Response System:** The proposed EPD Waiver amendment would make this system available to beneficiaries in the Medicaid State Plan as well as those in the EPD Waiver. However, an emergency response system cannot prevent injuries in the same way that a personal care aide can. People who need substantial assistance with activities like walking, transferring, using the toilet, and bathing will only be able to notify emergency services in the event of an accident.

Conclusion

Legal Aid urges DHCF to practically assess the capabilities of alternative EPD Waiver services to meet the needs of beneficiaries currently receiving over 16 hours per day of PCA services before implementing the cap. We also urge the agency to consider allowing PCA services in excess of 16 hours per day on an individually-determined, as-needed basis and allowing waiver participants who currently receive 17 to 24 hours of PCA services per day to continue receiving those services after the changes are implemented.

Further, we ask DHCF to ensure that RN assessors are adequately trained to deliver the assessment in a consistent manner and to consider allowing these nurse assessors the discretion to recommend a higher level of assistance than what is captured by the InterRAI assessment tool. We also ask the agency to identify a way to account for other gaps in the current assessment tool that might lead to insufficient Personal Care Aide service hours.

¹⁴ Application for 1915(c) HCBS Waiver: Draft DC.003.04.08 – April 04, 2020, p. 75 (https://dhcf.dc.gov/sites/default/files/dc/sites/dhcf/page_content/attachments/EPD-Waiver-Amendment-April-2020.pdf).

¹⁵ *Id.* at p. 86.

Legal Aid urges the Committee to exercise its oversight authority to determine how many EPD Waiver beneficiaries will be affected by limiting PCA services to 16 hours per day and whether the other EPD Waiver services are practically equipped to adequately meet the needs of affected beneficiaries for up to 8 hours each day.