MEMORANDUM

TO: Jamie Buchenauer, Jill Vovakes, and Kristen Wierman, Office of Long-Term Living

FROM: PA Health Law Project, Community Legal Services, CARIE, PA Health Access Network, Jewish Healthcare Foundation, Ann Torregrossa

DATE: May 27, 2021

RE: **Suggestions from Participant Advocates regarding Priorities for American Rescue Plan Funding**

OLTL has requested input from CHC participant advocates regarding priorities for the use of funds from the American Rescue Plan (ARP). In response to this request, advocates have identified the following priorities for OLTL's consideration:

1. **Reducing the Waiting List for Pennsylvanians with Intellectual Disabilities**

   PROBLEM: Once they are found to be financially and clinically eligible, thousands of Pennsylvanian adults with physical disabilities can receive in-home services and supports relatively quickly. There is no waiting list for them. However, thousands of Pennsylvanians living with autism or an intellectual disability (and their families) have their lives put on hold as they remain on a waitlist, in some instances for years, to receive the critical services and supports that can help them lead productive and healthy lives. According to the PA Waiting List Campaign, nearly 13,000 people with intellectual disabilities are on a list awaiting these services. More than 5,000 list members were in the "emergency" category, meaning they need services immediately– or by no later than six months.

   RECOMMENDATIONS*:* We strongly urge the state to use American Rescue Plan (ARP) funding to accommodate more individuals. The new CMS guidance gives states flexibility to use (ARP) funding to "enhance, expand or strengthen HCBS services." Reducing the ID waiting list for services falls squarely into the examples offered by Biden administration officials.

   There are various ways to reduce the waiting list. Not all the new slots have to be for the Consolidated Waiver. We are open to additional discussion about the methodology to reduce the waiting list.

   This approach will likely benefit some CHC participants with intellectual disabilities who might be better served in one of the ODP-operated waivers.

2. Supporting and Rebuilding Direct Care Workforce

PROBLEM: The COVID-19 pandemic has exacerbated long-standing shortages of qualified DCWs. Many DCWs stopped working outside their households during the pandemic due to disruption of schools/childcare services or out of concern for vulnerable family members. At the same time, many HCBS participants and their families were not allowing DCWs from outside the household during the pandemic.

As pandemic-related restrictions ease and vaccination rates rise, some DCWs may return to work. However, many DCWs may be hesitant or unable to return to work due to a) lingering child care issues and b) low wages that fail to compete with other available employment or generous unemployment benefits. Meanwhile, demand for DCWs might be elevated in the short term because of participants who are unable to return to adult day centers due to closures or capacity limitations, as well as continuing consumer preference to avoid congregate facilities in the wake of the pandemic.

RECOMMENDATIONS:

- Use ARP funding to offer sign-on bonuses or other short-term incentive pay for new DCWs or DCWs who are returning to work after the pandemic. To encourage new DCWs to stay in the workforce, the incentives could be spread out over time (ex: additional bonuses after working a certain amount of time) rather than given as a one-time bonus.
- Use ARP funding to waive fees associated with hiring/onboarding new DCWs, specifically fees that usually are paid by the employee (ex: background check/fingerprinting fees, administrative fees). To the extent these fees are an obstacle to would-be DCWs, waiving the fees might speed up their entry into the workforce.
- Use ARP funding to finally raise hourly wages or cover expanded benefits for DCWs. An across-the-board raise would make DCW wages more competitive with the broader job market and help alleviate the shortage, at least in the short term. However, for this to be sustainable, the State would have to find additional funding to support the raise after the ARP funds are exhausted. The State would also need to take care to ensure any increased funding is actually passed through to DCWs, rather than agencies.

3. Reimbursing Caregivers for Pandemic-Related Expenses

PROBLEM: The pandemic made it unsafe or impossible in many cases to bring outside caregivers into a household. At the same time, adult day centers closed abruptly. This left many families of HCBS recipients to shoulder caregiving responsibilities with only limited support. Family members ended up taking on additional caregiving hours, both paid and unpaid. In some cases, family

members ended up moving or relocating to be able to provide care. Due to delays and shortages in providing PPE through CHC-MCOs, many family members also had to take on the additional cost of purchasing PPE out-of-pocket.

RECOMMENDATIONS:

- Use ARP funding to provide one-time bonuses to family members who stepped in to provide additional care.
- Use ARP funding to reimburse family members for expenses incurred as a result of the pandemic, such as PPE or moving/relocation expenses. Because family members may not have receipts of these expenses, the Department will have to come up with a suggested award where proof of expenses is not available.
- Use ARP funding to temporarily expand respite services, to support families taking on additional caregiving.

4. Enhancing Nursing Home Transition/Diversion Resources

PROBLEM: Advocates have long expressed concern that participants are going into nursing homes or being kept in nursing homes unnecessarily due to intractable delays in the application process for HCBS and the NHT process. These concerns became exponentially more urgent as COVID tore through nursing homes with deadly efficiency. The pandemic has laid bare the need for reform to keep participants out of nursing homes where feasible and get them out as quickly as possible. While most of this population are adults, it includes a small but vulnerable number of children living in pediatric nursing homes who need the opportunity to leave institutional care and experience family life.

RECOMMENDATIONS:

Use ARP funding to enhance nursing home transition and diversion resources:

- Provide additional funding for NHT services, including increased staffing for NHT teams as well as resources like home modification, housing, and relocation expenses.
- Provide access to additional equipment or devices that could support NHT. The May 13 State Medicaid Director letter from CMS listed numerous suggestions for use of ARP funding, including “Providing eyeglasses, wheelchair transfer boards, and adaptive cooking equipment to address functional needs, promote independence, and/or support community integration.”
- Fund Medicaid-housing partnerships and create incentives for CHC-MCOs to develop partnerships with community-based organizations that provide accessible housing. This is another suggestion from the State Medicaid Director letter.

- Allow deemed/presumptive/expedited eligibility determination for HCBS applicants who have been found NFCE and provide preliminary proof of income/resource eligibility. This would allow applicants to start receiving services as soon as they are found NFCE, without having to wait for the CAO to complete the five-year look back.
- Provide funding for expedited or emergency home modifications
- Allow HCBS applicants to spend down excess income to the Special Income Level (300% of the federal SSI rate). Right now, applicants can spend down excess income to qualify for MA nursing home care but can only qualify for HCBS by establishing a spend-down trust (and some individuals cannot qualify even through a spend-down trust). Eliminating the additional obstacles to qualify for HCBS would help avoid unnecessary NH placements and help participants with higher incomes – who would otherwise not qualify for services needed to leave the NH – transition to HCBS. This could initially be rolled out as a pilot program, to enable the Department to get a better understanding of the costs before deciding whether to allow spend-down permanently.
- Fund guardian fees for HCBS participants, either by adding it as a waiver service if permissible or by separately funding it. Currently, monthly fees can be paid to nursing home residents' guardians for their services through a $100 per month deduction in the determination of the resident's payment toward the cost of LTC facility services. However, there is no mechanism to pay guardian fees for HCBS participants, who are low income and generally cannot afford to pay these fees themselves. This creates a strong incentive for guardians to place such individuals in nursing facilities and keep them there, in violation of their right to receive services in the least restrictive setting. Funding guardianship fees for HCBS participants, as well as nursing home residents, would eliminate this disparity.
- Increase the guardianship fee deduction in the determination of payment toward cost of long term care facility services to $250. This deduction has been set at $100 for many years and is no longer adequate. Because it is so low, professional guardians spend little time participating in care planning conferences, monitoring whether the residents' needs are being met or considering whether the resident could transition to the community. Increasing this deduction would make it feasible for courts to expect and require a higher level of involvement and attention from guardians, to the benefit of individuals under guardianship. It would also give guardians an incentive to be more cooperative with the NHT process, particularly if OLTL also implements the above suggestion to fund guardianship fees for HCBS participants.
- Use ARP funding to invest in tenancy sustaining services, such as funding for home maintenance or chore services for those without informal

supports. This could be launched as a temporary pilot program, to examine the feasibility of creating a broader program for HCBS applicants who don't meet the NFCE criteria but nevertheless are at risk of losing their housing without IADL assistance.

- The CMS guidance included a suggestion for "Testing the impact of assistive technologies on the need for in-person supports." Implement a pilot program using remote monitoring technology to supplement care for HCBS participants with supervision needs. The purpose of this program would be to evaluate whether remote monitoring could improve safety outcomes for participants who would otherwise require hard-to-staff 24-7 PAS coverage or nursing home placement.
- Implement suggestion from CMS guidance to "Provide nursing facilities or other institutional settings with funding to provide adult day services, respite care, or other HCBS."

5. Implementing Lessons Learned from Pandemic

***PROBLEM**:* The pandemic highlighted disturbing deficiencies in the infection control and disaster preparedness within nursing facilities, which has implications for HCBS, LIFE Programs and adult day centers (ADCs) as well. The pandemic also shed a light on the devastating impact social isolation can have on HCBS participants.

RECOMMENDATIONS: Use ARPA funding to help ADCs, LIFE Programs and home care agencies implement these lessons learned during the pandemic, including:

- Upgrading ADC facilities and equipment to improve infection control. ADCs could use the funding to better prepare not only for pandemic emergencies such as COVID, but also existing communicable disease threats such as seasonal influenza.
- Developing high-quality training programs for dementia care/competency and infection control, using lessons learned during pandemic. ARP funding could be used to hire consultants and develop training materials or videos, which could be used to train future DCWs and ADC employees even after funding has run out.
- Implementing a pilot program that provides smart phones, tablets, computers, and/or internet activation fees to support community integration and reduce social isolation among HCBS and LIFE Program participants. In other words, invest in communication technology to help HCBS participants stay connected with distant family members. Such a program would likely require funding for training for participants with limited tech literacy and could be paired with a study to measure outcomes. Facilities/the Department could maximize the impact of the

ARP Funding by leveraging public-private partnerships with internet or telecom companies.

- Funding applied research regarding addressing deficiencies identified in the pandemic, such as infection control and social isolation.

6. Enhancing Support for Adult Day Centers

PROBLEM: Adult day centers sustained significant economic losses when they were forced to close during the pandemic, and many will continue to incur losses as they operate at limited capacity. At the same time, they will incur additional expenses during reopening in order to make safety enhancements. Without additional support, some adult day centers may not be able to remain open.

RECOMMENDATIONS:

- Use ARP funding to temporarily supplement existing rates for adult day providers, to compensate for shortfall caused by capacity limits and forced closures.
- Provide grants to cover the cost of COVID-related safety measures, including PPE, cleaning supplies, barriers/social distancing equipment, etc., to the extent these costs are not being covered through other funding sources. This should include both retroactive and prospective expenses.
- Fund sign-on bonuses, back-to-work bonuses, or other incentive pay for new and returning adult day center workers.

7. Making One-Time Technology Upgrades

PROBLEM 1: HCBS participants are required to go through annual redetermination of their financial eligibility, which often involves submitting updated financial records. In most cases, the CAO already has the participant's bank account information from previous years; nevertheless, participants are expected to obtain bank records and submit them to the CAO. This process is burdensome for participants, many of whom have cognitive or behavioral difficulties that make it difficult to navigate the redetermination process. Even when participants submit documents timely, they aren't always processed in a timely fashion and in some cases the documents seem to get lost altogether. In many cases, participants have lost their benefits because they didn't have support during redetermination, or because the case handler could not find the paperwork that was submitted.

RECOMMENDATION: Use ARP funding to make technological upgrades needed to streamline the redetermination process. This could include electronic verification of bank accounts using the Asset Verification System (AVS) and other resources already on file, eliminating the need for participants to submit additional information. AVS provides the information which CAOs currently obtain

by requesting a bank statement, namely the participant's current account balances. This effort could also include making system improvements to ensure information submitted by participants is transmitted to case handlers more quickly.

PROBLEM 2: There is currently no central way to track the status of grievances and appeals made by CHC participants. DHS and PDI have been unable to monitor the progress and required steps for grievances, appeals, external reviews, when notices are sent to consumers, if benefits are to be continued pending appeal, if notices have been sent to consumers' attorneys, when hearing are held, when fair hearing is, when external reviewers are appointed, when decisions are made, etc. This makes it challenging for OLTL and advocates to monitor compliance with appeal deadlines. It also leads to time consuming back-and-forth between advocates and the CHC-MCOs to determine the status of an appeal.

RECOMMENDATION: Use ARP funding to establish a centralized database, akin to a court docket, to track every stage of an appeal from the grievance request through fair hearing disposition. Each important step would be clearly indicated and required to be entered by the MCO, DHS fair hearing staff, or PDI external review. This would allow interested parties to see the status of any appeal at a glance and monitor whether time frames are being met.

8. Enhance Support for Medical and Non-Medical Transportation

PROBLEM: Many local transportation providers faced obstacles due to the decrease in ridership during the COVID-19 pandemic and adjustments to provide safe trips following protocols on cleaning of vehicles and limited rider capacity. Additionally, there continue to be many participants who are unfamiliar with transportation.

RECOMMENDATIONS: Use ARP funding to ensure that transportation providers are able to continue providing necessary trips across the state to medical appointments and for other non-medical needs as dictated by person-centered service plans such as trips to the grocery store or religious gatherings:

- Reimburse transportation providers for COVID-related expenses (ex: vehicle cleaning and disinfecting, modifying vehicles to comply with social distancing protocols), to the extent these expenses are not covered by other sources. This reimbursement should include both retroactive and prospective expenses.

- Provide grants for local MATP providers to build their fleets, especially power-chair accessible vehicles.
- Invest in outreach to participants to ensure they are familiar with transportation benefits and how to access them.

9. Implementing Racial Equity Reforms

PROBLEM: The COVID pandemic has had a disproportionate impact on communities of color. Data from the CDC shows that nationwide, African American patients made up 13.7% of COVID-related deaths, despite making up only 12.5% of the population. Latinx patients made up a whopping 28.8 percent of COVID cases and 18.7 percent of deaths, despite only being 18.45 percent of the population. Meanwhile, African Americans and Latinx make up only 8.9 and 13.8 percent, respectively, of the population that has received at least one dose of the COVID-19 vaccine.

RECOMMENDATIONS:

- Use ARP funding to temporarily exclude primary residences from estate recovery. Primary residences are already excluded as resources for purposes of HCBS eligibility but are subject to estate recovery unless there is a surviving spouse, disabled adult child, or caregiver-relative who qualifies for a hardship exemption. This perpetuates racial disparities in wealth by preventing HCBS participants of color from being able to pass property down to future generations. Exempting primary residences from estate recovery would ease this disparity.
- Race and ethnicity overlap with many immigrant populations with low English proficiency. To this extent, use ARP funding to provide increased access to translated documents, language lines, and other interpretation services that are culturally competent.
- Improve and expand the state's data collecting activities and requirements to collect a greater breadth and depth of data concerning LTSS use of and outcomes broken out by participants' race and ethnicity. This data is needed in order to identify disparities, which should then be analyzed and addressed through policy reform.