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Olmstead Planning Committee  
Executive Office of Health and Human Services  
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**RE: Medical obstacles to remaining in home and community  
for individuals with disabilities**

Dear Committee Members,

Health Law Advocates (HLA) respectfully submits the following comments to the Olmstead Planning Committee regarding updates to the Commonwealth of Massachusetts's Olmstead Plan. HLA is a non-profit, public interest law firm that provides free legal assistance to low-income Massachusetts residents who face barriers to accessing health care and coverage. Our clients represent the full spectrum of people with disabilities, from those who need minimal assistance to adults and children who require intensive, on-going care and assistance with all activities of daily living (ADLs).

We have identified four health care-related barriers experienced by our clients with disabilities, which affect their ability to stay in the community of their choosing. Below is a brief outline of each issue and client stories that illustrate the impact on individuals' ability to maintain their well-being and medical safety at home.<sup>1</sup>

**Durable Medical Equipment**

HLA has many clients who struggle to access medically necessary durable medical equipment (DME) that allows them to maintain their health, safety, and independence in community-based settings. DME products can range from mobility devices – like wheelchairs or crutches – to equipment that an individual must wear on their body at all times, such as a heart monitor or feeding tube. Many of HLA's clients experience long delays in prior approvals to obtain DME. Others must navigate complicated systems to prove medical necessity, seek medical records from numerous providers – often at a cost to the client – obtain multiple referrals, and keep track of large amounts of paperwork. Delayed access to medically necessary DME can seriously affect consumers' health, safety, and compromise their ability to live at home.

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<sup>1</sup> Client's names and some personal information were changed to protect confidentiality.

• S.L. was a moderately healthy fifty-two-year-old man with quadriplegia who became bed-bound after his wheelchair ceased operating. MassHealth denied his prior authorization request for a new wheelchair because a company had delivered a “new” chair several years earlier. However, this “new” chair did not physically fit his body or meet his medical needs by having proper strapping and a lift-system. He made several attempts to return it at the time, but the company failed to take it back. We appealed the denial, but the long appeal process caused him to remain bed-bound for more than seven months by the time the hearing took place in June 2016. During those seven months, S.L. experienced a marked decline in physical and mental health, as well as diminished cognitive functioning. Although MassHealth agreed to pursue a new prior authorization, S.L.’s health had declined to such an extent that he became hospitalized soon thereafter. Since then, he has bounced between home, rehabilitation facilities, and the hospital. He has not been well enough to be “fitted” for a new wheelchair.

### **PT-1 Medical Transportation**

Many of HLA’s clients with disabilities rely on PT-1 medical transportation to access treatment. Any delay or administrative hurdle to obtaining medically appropriate transportation greatly affects their ability to stay in their home. Very often, clients with disabilities are unable to access public transportation; either because their disability prevents them from meaningfully using public transportation, or because they live in a part of the state without a comprehensive public transportation system. In these instances, clients rely on PT-1 transportation to access medical care. However, significant paperwork, bureaucratic delays, and administrative errors cause access barriers. Many medical providers do not understand the PT-1 system and HLA intervention is required to ensure our clients can access the services they need. Streamlining this process would greatly improve the ability of individuals with disabilities to access medically necessary care and stay in their communities.

Additionally, due to the bidding process for transportation vendors, it is very difficult to establish continuity of experience in PT-1 transportation services. Members receive no notice of when bidding occurs, or when a vendor they use is no longer an option in their area. These changes can cause significant disruptions in service provision for MassHealth members with specialized needs, especially those with behavioral health diagnoses that require routine care to maintain a safe baseline. Additionally, clients are often confused about how to register complaints or concerns regarding their PT-1 vendor, such as a vendor not honoring specific requirements written into the prescription (i.e. being a “ride-alone” client, riding in a car where there is no smoking or residual smoke smell). There is little accountability and transparency regarding which vendors have complaints filed against them. More clarity around vendor changes, a streamlined process for individuals to register their complaints with PT-1 vendors, and additional training of the provider community would greatly improve access for individuals with disabilities.

- A.P. is a 51-year-old MassHealth member with bipolar disorder and other intellectual and emotional impairments who lives in Worcester County. A.P.'s primary care provider (PCP) prescribed medically necessary cognitive behavioral therapy and her in-network provider was located in Boston. Without PT-1 transportation, A.P. would not have the ability or means to access this medically necessary treatment, which is essential to managing her diagnoses and allowing her to remain in her community.

### **Personal Care Attendant (PCA) Program versus the Home Health Aide (HHA) program and other PCA Issues**

We have many clients who struggle with the administrative processes associated with the MassHealth PCA program. The consumer-directed nature of the program requires a member to take on significant responsibility regarding the hiring and firing of employees, training their workers and directing their personal care, and completing and submitting timesheets. While many people relish the independence this program affords them, many others are overwhelmed and confused by the administrative processes, including those who would not qualify for a surrogate based on their disability. While the individual hires the PCA, they still must deal with a PCM agency who handles the paperwork involved with hiring, firing, and timesheets. Often, HLA must intervene between our clients and PCMs because communication has broken down, paperwork has been lost or mishandled, and our clients are unable to access the PCA services to which they are entitled. Many of our clients are overwhelmed and confused by the entire PCA process.

HLA's client work suggests that the PCA program is inappropriate for some members who require assistance with ADLs. Self-direction and independence are the hallmarks of the PCA program and not all members with disabilities can meaningfully direct their personal care. The surrogacy program is a crucial means of lightening the administrative burden for members who are unable to manage the program without assistance. However, the purpose of a surrogate is not to stand-in completely for a member, but to facilitate the administrative operation of the program. Members who are cognitively impaired to an extent where they cannot communicate their care needs to a PCA are not good candidates for the PCA program. By definition, a PCA is an "unskilled" caregiver who requires training by the personal care management agency, the member, and (where appropriate) the surrogate. Unskilled caregivers, however well-meaning, can pose a serious risk to members who, by virtue of their disability, are unable to express that a specific ADL is being performed inadequately or incorrectly. Engaging a surrogate who has only intermittent interaction with the member and their workers is an inadequate substitution for a member who can meaningfully direct their own care. In such cases, a trained caregiver who is supervised by a medical professional may be required.

MassHealth's recent shift away from approval of Home Health Aide (HHA) services to PCA services is inappropriate for some members, especially those who are unable to speak for themselves. HLA has numerous clients who are children and teenagers with severe cognitive disabilities and chronic medical

conditions who are being pushed into the PCA program by MassHealth. Many of these clients are unable to self-direct their personal care are at serious risk of institutionalization because they are not able to access the services and supports they need to remain in their home and community.

- A.K. is a severely disabled, non-verbal 14-year-old who came home in February 2016 after spending 7 years in two residential facilities. He left each of the facilities because he was failing to thrive and his life skills had seriously degraded. MassHealth's Home Health Aide program has been critical to ensuring his safety and well-being at home. Since coming home, A.K. has gained significant weight and recovered many life skills, though he remains non-verbal. His presence has enriched the life of his family and community. Regular nurse's visits are critical to monitor his status since his care regimen changes frequently (he is on 15 medications). Home Health Aides (HHAs) attend to A.K.'s care needs during the night while his mother and siblings sleep. He does not sleep during most of the night and he requires multiple rounds of oxygen, as well as assistance with feeding, bathing, dressing, and diapering. Previously, he was in the PCA program, but the caregivers' lack of training, medical supervision, and direction from the patient ultimately rendered the program inadequate. He had to go to a facility, tearing the family apart. According to A.K.'s mother, the HHA program has been key to ensuring his health and safety so he can thrive at home.

#### **Low Reimbursement Rates for Home Nursing**

Many of HLA's clients with disabilities, specifically those who are children, need skilled nursing services to stay safely in their homes. These nurses maintain DME, monitor the client for any new symptoms or reactions, and assist with medications and other minor in-home procedures (such as checking blood glucose) among other things. Our client work has revealed a significant and pervasive problem where individuals – particularly children with high medical needs – have been approved for home health hours that remain unfilled due to an acute shortage of nurses willing to serve MassHealth members in their homes. Nurses who possess requisite skills are unwilling to provide in-home services in large part because hospitals and other facilities offer better pay and benefits. This problem increases in severity in more rural areas of the Commonwealth where there are fewer providers. Unfilled nursing hours have a traumatic effect on consumers and their families. Often a parent or other family member has to step in to fill the void, exacting devastating financial and emotional costs on the family. Ultimately, some of these children are institutionalized because they are unable to access the medically necessary (and MassHealth-approved) skilled nursing hours that should allow them to stay in their homes.

- A.S. is a 9-year-old boy from Worcester who has significant mental and physical health issues that require in-home nursing care. Since 2013, A.S. has been covered for in-home nursing services through MassHealth's Community Case Management program (CCM). CCM authorized 65 hours per week of medically necessary skilled nursing care for A.S., however, his family is able to fill only 48 of these approved hours. Thus, more than one quarter of the hours remain unfilled. Forty-eight hours is a recent improvement: for most of 2016, A.S. had nurses attending to his needs only 30 hours per week, which was less than half the hours that MassHealth determined were necessary to

maintain his safety at home. Due to low reimbursement rates, nurses in the area with the requisite skills and training are far more likely to work at hospitals where they receive higher pay and better benefits. Both A.S.'s MassHealth caseworker and nurse managers at CCM have told A.S.'s mother, M.S., that there is nothing they can do to fill his nursing hours. The hours remained unfilled even after CCM offered modest bonus pay allowed by the regulations. M.S., who does not have a background in nursing, attempts to fill the gaps in her son's care. She has been unable to maintain a full-time job in over a year because she has attempted to fill the gaps in A.S.'s care. Her family has been surviving on a single income, which has made it very difficult for all family members to maintain their health and wellbeing.

Thank you for the opportunity to offer input as the Commonwealth updates its Olmstead Plan.

If you have any questions, please do not hesitate to contact either one of us.

Sincerely,



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