

Empowering People to Lead Systemic Change

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Finance Committee Senate Bill 0920: Public Health – Maryland Interested Parties Advisory Group – Establishment

March 4, 2025

POSITION: SUPPORT

Thank you Madame Chair Beidle and Committee Members for the opportunity to provide written testimony for Senate Bill 0920: Public Health – Maryland Interested Parties Advisory Group - Establishment. Disability Rights Maryland (DRM – formerly Maryland Disability Law Center) is the federally designated Protection and Advocacy agency in Maryland, mandated to advance the civil rights of people with disabilities. DRM works to increase opportunities for Marylanders with disabilities to be integrated into their communities, live independently and access high-quality, affordable health care.

The development of home and community-based services (HCBS), along with the pivotal 1999 *Olmstead v. LC* Supreme Court decision, served as a critical turning point in ensuring that individuals with disabilities have a choice in where they received their care. Many HCBS participants rely on direct care workers to provide them with essential care and assistance within the comfort of their home. Unfortunately, direct care workers are undervalued within the system, facing low wages and benefits and very limited labor protections. These various barriers make it difficult for individuals with disabilities to access the care that they need to not only thrive within the community, but also survive.

This widespread access to care issue has been addressed at the federal level. In 2024, the Centers for Medicare and Medicaid Services (CMS) published a federal rule entitled "Ensuring Access to Medicaid Services" (or "Access Rule"). Among other solutions, this rule specifically calls for the establishment of an Interested Parties Advisory Group (IPAG) in every state. The intent behind this group is to address the link between access to quality care and the wages and working conditions of the direct care workforce.

Senate Bill 0920 will bring Maryland into compliance with the federal rule, but also ensure that the barriers to accessing quality care are addressed and resolved in Maryland. While direct care workers consistently voice their concerns about low wages and poor working conditions, these concerns are often ignored. This blatant disregard causes many direct care workers to leave the workforce for better, more stable working conditions, creating a shortage of direct care workers. Individuals with disabilities are directly impacted by this shortage and are not able to access

¹ Olmstead v. LC, 527 U.S. 581 (1999)

² Fact Sheet, Ensuring Access to Medicaid Services Final Rule (CMS-2442-F) | CMS. https://www.cms.gov/newsroom/fact-sheets/ensuring-access-medicaid-services-final-rule-cms-2442-f ³ 42 C.F.R. §447.203

⁴ Fact Sheet, Ensuring Access to Medicaid Services Final Rule (CMS-2442-F) | CMS. https://www.cms.gov/newsroom/fact-sheets/ensuring-access-medicaid-services-final-rule-cms-2442-f

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medically necessary care in their home. However, the establishment of an IPAG in Maryland will make sure that the concerns of the direct care workforce is recognized, addressed and resolved. In turn, a more stable workforce will be created, affording consumers who rely so heavily on these workers access to the quality care that they are entitled to.

Additionally, this bill ensures that HCBS consumers are included in the efforts to resolve the barriers to accessing quality care. Under this bill, Maryland's IPAG will consist of consumers and direct care workers, along with representatives of consumer and worker organizations, a provider association, a member of the public and a non-voting member from the Division of Health Care Financing and Medicaid with advanced data literacy experience. The diversity of voices on this advisory group will ensure that all individuals who are involved in the provision of HCBS are represented when working to improve access to quality care in Maryland. Specifically, the inclusion of HCBS consumers will help to ensure that the annual recommendations that will be made to the Governor and the General Assembly will also directly address the access to care issues consumers experience daily. In a system that has historically ignored the voices of individuals with disabilities, this opportunity to participate is incredibly critical in ensuring that one of the most underserved and underrepresented populations have access to the quality care that they not only need, but also deserve.

The ability to access necessary and quality health care without barriers is essential in ensuring that all individuals can lead the life they want and deserve. Unfortunately, individuals with disabilities have been in a constant cycle of oppression, inequity and powerlessness that limits such an ability. Senate Bill 0920 can help ensure that Maryland is a part of the solution to ending that cycle, ultimately helping to create a future that allows people with disabilities to feel respected and equal in society.

For these very reasons, DRM strongly supports Senate Bill 0920 and urges a favorable report.

Respectfully,

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