Commission on the Status of Persons with Disabilities Long-Term Services & Supports and Health Equity Subcommittee Meeting Minutes

Date of Meeting: Monday, August 25, 2025

Time: 11am to 12pm

Location: Virtual Meeting (Zoom)

Members Participating Remotely				
1	Carl Richardson (Co-Chair) – ADA Coordinator, Massachusetts State House			
2	Charlie Carr (Co-Chair) – Legislative Liaison, Disability Policy Consortium			
3	Chris White – CEO & President, Road to Responsibility, Inc			
4	4 Oz Mondejar – President, Mucho Gusto Consulting			
Members Not Present				
5	Angela Ortiz – Executive Director, MA Health Council			
6	6 Honorable Denise Garlick			
Additional Commissioners Present				
Nancy Garr-Colzie - Member, Worcester Disability Commission; Board Chair, Center for				
Living and Working				
Representative Vanna Howard – House of Representatives				
Representative John Marsi – House of Representatives				
Ann Lynch – Massachusetts Attorney General's Office				
Leo Sarkissian – The Arc of Massachusetts				
Le	Lexi Semanchik – State Treasurer's Office			

Action Items		Person Responsible
1	Invite Collin Killick and Bill Henning to	Charlie
	speak about the consequences of Covid	
	regarding health equity for people with	
	disability and lessons learned	

Agenda

- 1. Welcome, Roll Call, Approval of Minutes
 - Minutes have been approved after motion.
- 2. Presentation: An Overview of Community Living Research at the Lurie Institute for Disability Policy
 - Monika Mitra, Director, Lurie Institute for Disability Policy, Nancy Lurie Marks Professor of Disability Policy
 - Joseph Caldwell, Senior Research Scientist
 - Sydney Pickern, Project Manager, Community Living Policy Center
 - Teresa Nguyen, Project Manager, Community Living Equity Center

• Laurin Bixby, Scientist

Highlights:

- The Lurie Institute focuses on research that informs policies, programs, and practices to enhance the lives of people with disabilities across the lifespan.
- The Community Living Policy Center (CLPC) and the Community Living Equity Center (CLEC) both aim to improve home- and community-based services (HCBS), promote equitable access, and ensure that research includes the participation and perspectives of individuals with disabilities.
 - o Link to the CLPC Publications page: https://heller.brandeis.edu/community-living-policy/research-policy/index.html
 - o Link to the dashboard: https://heller.brandeis.edu/community-living-policy/clec/community-living-equity-dashboard-home.html
- Research findings are widely shared with community members and policymakers to promote transparency and collaboration.

Key focus areas:

- Current study interviewing 30 direct care workers nationwide to understand challenges in recruitment and retention. Will have research brief next spring. We will invite Sydney Picker to present at Workforce Supports subcommittee. Participant screener link: https://brandeis.gualtrics.com/jfe/form/SV-8ivsQaTFTSxXz9k
- Research on affordable and accessible housing options, including creative models such as social housing and braided funding approaches.
 Collaboration with partners such as DREDF to examine ways to expand and sustain inclusive housing opportunities.
- Analysis of racial and ethnic disparities in self-directed home- and community-based services using NCI-IDD and NCI-AD data.
- Conducting interviews and focus groups to understand barriers and facilitators for people of color transitioning from institutional to community living.
- Community Living Data Dashboard
 - An interactive, accessible dashboard designed with input from people with disabilities.
 - o Provides data on who needs and receives long-term services and supports across demographics and states.
 - o Identifies that approximately 17.6 million U.S. adults (6.8%) need LTSS, while only about 6.4 million (10.7% of Medicaid beneficiaries) currently receive services, indicating significant unmet need.
- Discussion on improving the accuracy of race and ethnicity data in Medicaid systems, as current data are often incomplete or underreported.
- Advocacy for states to strengthen data collection and reporting standards to improve equity in community living services.

Discussion points:

- Discussion of Medicaid waivers, including the 1115 and 1915(G) waivers, and how they impact access to HCBS.
- Mention of Mathematica CMS standards as potential benchmarks for quality improvement.
- Oz expressed interest in connecting with Monika Mitra, given his work with the Health Equity Compact.
- A recommendation was made to connect with Applied Self Direction's new initiative, *The Self Direction Center*, for future collaboration opportunities.
- Upcoming <u>Lurie Institute public lecture</u> scheduled for October 28.

2025 Meeting Dates

• November 17, 11am-12pm