Lurie Institute for Disability Policy

Community Living Equity Center: Overview

September 2022

Introduction

The Community Living Equity Center (CLEC), housed at the Lurie Institute for Disability Policy at Brandeis University, will address knowledge gaps about inequities in community living and participation experiences and outcomes faced by disabled people of color. CLEC will do this by creating interventions to address equity, leveraging existing and new data sources, developing new policy and systems-change initiatives, and through active dissemination of findings and trainings for stakeholders.

CLEC is collaborating with partners, including Human Services Research Institute, Disability Rights Education and Defense Fund, Justice in Aging, and the Autistic Self Advocacy Network, to conduct cross-disability, multidisciplinary research—and to share its findings with a wide audience. To make sure that our research puts the community's needs first, we will seek the expertise of the CLEC community advisory committee to guide all our research and knowledge-translation activities.

CLEC is conducting five research projects that will contribute to our understanding of community-living participation outcomes and the experiences of disabled people of color (and their intersecting identities) through rigorous, population-based research.

Research Projects

Racial and Ethnic Disparities in Home and Community-Based Services Access and Utilization

Investigators: Mitra (Principal Investigator), Akobirshoev, Caldwell

We will understand the differences by race/ethnicity in the prevalence of long-term services and supports (LTSS) needs, racial and ethnic disparities in access to and utilization of Medicaid home and community-based services (HCBS), and disparities in access and utilization to Medicaid HCBS associated with the extent to which states have rebalanced their LTSS systems. This will be done by analyzing the American Community Survey and Medicaid data through which states have rebalanced their LTSS systems. Findings will be disseminated through the Equity and Community Living Data Dashboard, an accessible, interactive data dashboard.

Barriers and Facilitators in Access to Home and Community-Based Services for People of Color

Investigators: Heyman (Principal Investigator), The, Nguyen

To better understand the barriers and facilitators that disabled people of color experience in access to HCBS, qualitative interviews will be conducted with disabled people of color who have experienced placement in nursing homes and other institutions and then transitioned to the community. In addition, focus groups will be held with transition coordinators and state officials assisting individuals with community transitions. Lived Experience Experts will be hired and engage in all aspect of this research.

Self-Direction and Community-Living Outcomes for People of Color

Investigators: Caldwell (Co-Investigator), Croft (Co-Investigator), Nguyen

To explore equity in access, systemic barriers, and facilitators in community-living outcomes, we will analyze National Core Indicators–Intellectual and Developmental Disabilities (NCI-IDD) and National Core Indicators–Aging and Disabilities (NCI-AD) data as well as conduct qualitative interviews with people of color self-directing their HCBS. We will also hold focus groups with self-direction professionals and community-based organizations serving communities of color.

Promising Practices in Peer Support Models to Advance Equity in Community-Living Outcomes for People of Color

Investigators: Breslin (Co-Investigator), Yee (Co-Investigator)

We will conduct an environmental scan to identify promising practices in peer-support models to address equity and improve access to HCBS and community-living outcomes for people of color. At least three in-depth case studies of promising practices will be identified that can inform interventions, policy, and practice to advance equity in community living.

Policy Analysis and Development to Advance Community-Living Equity

Investigators: Kean (Co-Investigator), Christ (Co-Investigator), Robinson

Workgroups of community living and equity policy experts will be convened to: identify and analyze pressing topics of interest, study policies and existing proposals to amend policy, review literature relevant to policy, and develop policy briefs with recommendations to advance equity. Proposed topics: improving HCBS data, reentry from jail or prison and HCBS, intersection of immigration and HCBS policy, and access to HCBS for American Indian and Alaskan Native populations.

Accessibility of Dissemination Materials and Presentations

We will translate and share our research findings with a variety of audiences. Our dissemination efforts will include an online data dashboard that provides information for people with disabilities, advocates, family members, and professionals interested in community-living equity, as well as a series of webinars geared to policymakers and advocates. We will also seek guidance from our community advisory committee, create accessible documents for people with a range of disabilities and knowledge levels, and use multiple delivery methods (e.g., plain-language writing, live captioning, American Sign Language, language interpretation, images and graphs, videos with closed captioning) so that our materials reflect the experiences, accessibility needs, and priorities of the communities we support.

Contact CLEC

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