

An Overview of Community Living Research at the Lurie Institute for Disability Policy

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Community Living Equity Center
Centro para la Equidad en Vida Comunitaria



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Objectives

- **Introduction to Lurie**
- **CLPC Introduction**
 - **Housing and direct care workforce**
- **CLEC Introduction**
 - **Self-direction and nursing home transitions**
 - **Community Living Data Dashboard**
- **Q&A**



Lurie Institute for Disability Policy

Working to improve the lives of people with disabilities across the lifespan

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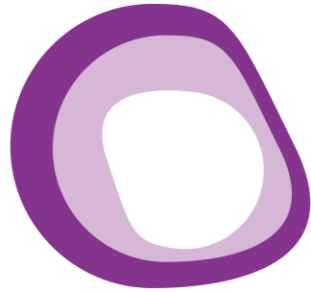
Our Research

helps **shape** policies, programs and practices which **improve** the lives of people with disabilities across the lifespan.

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National Center for
**Disability &
Pregnancy Research**



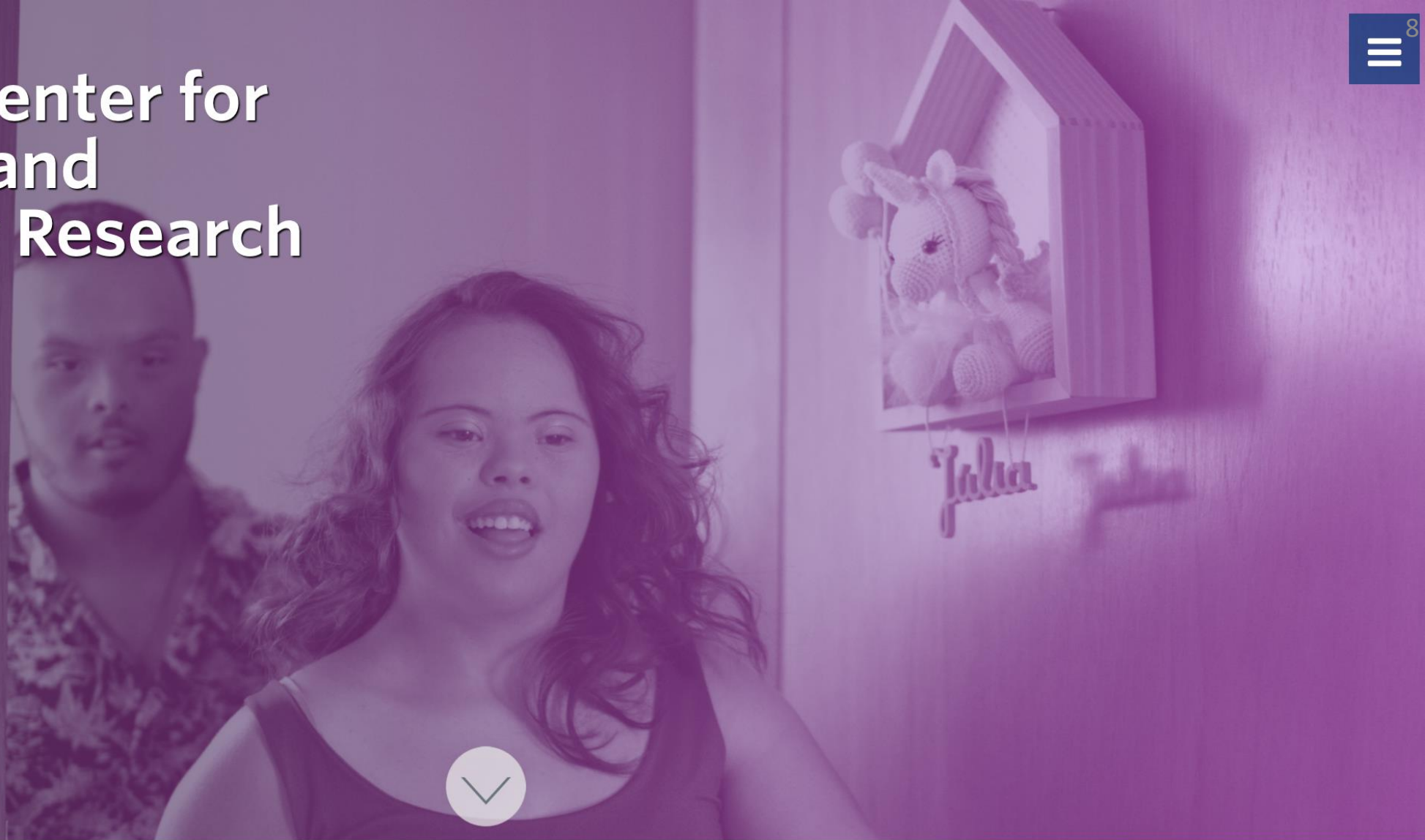
National Research Center for
Parents with Disabilities

Centro Nacional de Investigación para
Padres con Discapacidades



**Community Living
Policy Center**

National Center for Disability and Pregnancy Research



Improving disabled people's pregnancy experiences and outcomes through research, training, and education



National Research Center for Parents with Disabilities

Parents Empowering Parents

Padres Empoderando a Padres



The National Research Center for Parents with Disabilities conducts research and provides training and technical assistance to improve the lives of parents with



We offer resources to support [parents](#) with disabilities, and information about working with parents with disabilities for [social workers](#), [researchers](#) and [legal](#)



The Center for Parents recognizes that parents with disabilities know what they need. We are guided by the principle "nothing about us without us."



Aims to improve policies and practices that **promote community living** outcomes for individuals with disabilities.

The Community Living Policy Center Overview

- Background on the CLPC
- Research led by people with disabilities
- Unique community engagement approach
- Research focused on Medicaid HCBS and LTSS
- Policy advancement opportunities
 - **Money Follows the Person Example**



Community Engagement Approach

- **Participatory leadership of disability organizations and individuals with disabilities**
 - **Collaboration with disability and aging advocacy organizations and coalitions**
 - Disability and Aging Collaborative
 - Equity Advisory Committee
 - **Engagement with Members of Congress, Administration, and Policymakers**
 - Development of policy, regulations, technical assistance
- **Autistic Self Advocacy Network**
 - **Disability Rights Education and Defense Fund**
 - **Disability Policy Consortium**
 - **AUCD**
 - **ADvancing States**
 - **Centene Corporation**
 - **Asian Americans with Disabilities Initiative**
 - **The Arc**
 - **Self-Advocates**
 - **Justice in Aging**

Direct Care Workforce Research and Policy Work

- **Current Direct Care Workforce Study**
 - Interviewing diverse DCWs on strategies to strengthen the workforce
 - Centering diverse workers with broad range of experiences
 - Recruitment still open
- **Interested Parties Advisory Group policy brief**
 - Access Rule's Direct Care Workforce provision
 - July 2026 Implementation
 - Unique opportunity to grow rate-setting and policy coalition
 - Brief will be available soon



Affordable, Accessible Housing Research and Policy Work

- DREDF key partner
- Largest barrier to community living for disabled people and older adults
- Research highlights creative solutions to affordable, accessible housing development:
 - **East Bay Innovations (braiding Federal funding)**
 - **Social Housing and building accessibility**
 - **Olmstead and housing creation**
 - **MA AHVP**



The Community Living Equity Center Overview

- The **Community Living Equity Center** (CLEC) examines barriers in access to community living services and support for underserved people with disabilities.
- The CLEC is focused on the following goals:
 - Generate detailed new knowledge about disparities in community living.
 - Develop or identify effective systems-change initiatives or other promising practices that reduce community-living disparities.
 - Serve as a national resource for community living and participatory research that recognizes the unique challenges faced by people with disabilities from traditionally underserved communities.



Self-Direction and Community Living Outcomes for People of Color

Analyses of NCI-IDD and NCI-AD data to examine racial/ethnic differences in the use of self-direction and impacts on community living outcomes.

Qualitative interviews with people of color self-directing their HCBS and focus groups with self-direction professionals and community-based organizations serving communities of color to explore equity in access and systemic barriers and facilitators to self-direction.



Approach to CBPR

Responsibilities of Workgroup Members:

- Develop research questions
 - Design study materials
 - Recruit people for the study
 - Design interview questions
 - Share study findings
 - Help us be mindful of language
 - Think through cultural values
-
- Workgroup members will meet for about 10 hours per year
 - Members will be compensated a yearly honorarium for their engagement



Community Living Equity Center

Centro para la Equidad en Vida Comunitaria

Telling YOUR story can help others and influence the future of self-directed services.

We're holding confidential interviews with disabled people of color who want to share their experiences hiring, training, and managing direct care workers.

**Interviews last between 1 and 1.5 hours.
Contact us to learn about participating!
Must be 18 years or older.**

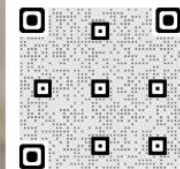
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Community Living Data Dashboard

- Provides advocates and policymakers with an understanding of who needs Long-Term Services and Supports (LTSS) and who receives Medicaid LTSS at state and national levels
- People with disabilities advised the development of the accessible and interactive dashboard at all phases of the design process
- Can apply filters to look at disparities (example: by age and race)

Why this Dashboard is Important?

People with disabilities deserve to live independently and in the community



Why does this data matter?

- Prior research on racial disparities in LTSS has primarily focused on nursing homes or Medicare home health rather than HCBS, due in part to substantial variation in HCBS across states and limited data.
- Lack of data hinders the development of policies and interventions to address the institutional bias and improve access to HCBS.
- Data is essential for “rebalancing” efforts that allocate Medicaid LTSS funds and services away from institutionalized care and towards community-based settings.



Who is this data relevant to?

- Advocates/Families (disability and aging communities)
- Policymakers
- Researchers
- HCBS/LTSS Providers
- Public Health Workers
- Direct Care Workers
- Other stakeholders interested in LTSS need and utilization

How can the Community Living Data Dashboard be useful for advocacy?

- Identify specific populations for targeted policy interventions
- Understand how current policies or litigation may disproportionately affect certain populations by race/ethnicity, sex, or age
- Defend Medicaid by providing estimates of who receives LTSS
- Use the demographic information in the dashboard to tailor messaging to specific audiences
- Protect Medicaid Expansion by showing who needs LTSS, including highlighting the percentage of people above the federal poverty level



Where does the data on who needs LTSS come from?

Who Needs LTSS?

- American Community Survey ([ACS](#)), 2021 5-year sample
- Collected by U.S. Census Bureau
- Nationally representative sample of U.S. adults



How do we define LTSS need using the American Community Survey data?

Someone is considered to have an LTSS need if they self-report one (or both) of the following types of disabilities:

- **Self-care Disability**: Because of a physical, mental, or emotional condition lasting at least six months, the person has serious difficulty dressing or bathing.
- **Independent Living Disability**: Because of a physical, mental, or emotional condition lasting at least six months, the person has difficulty doing errands alone such as visiting a doctor's office or shopping.



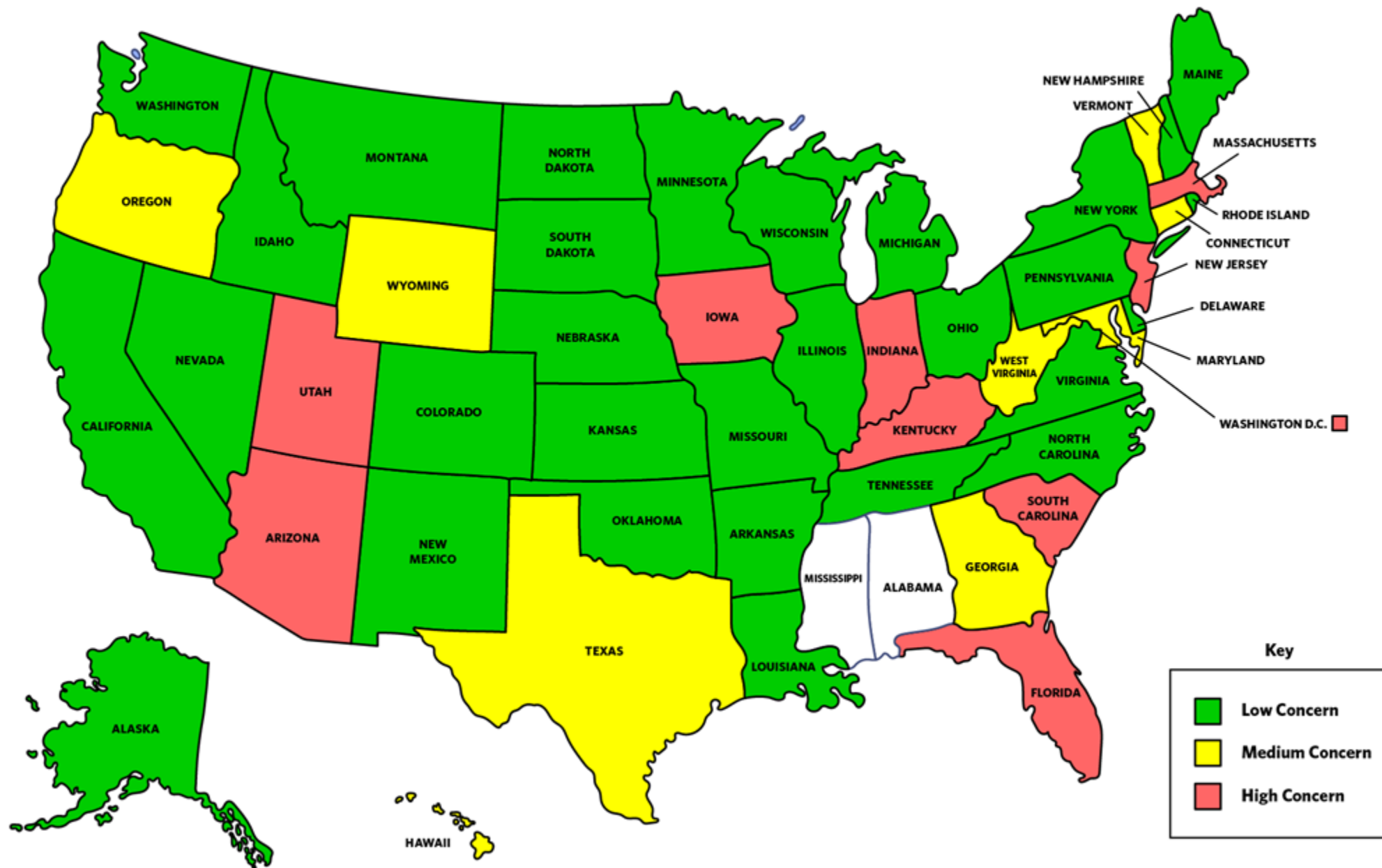
Where does the data on who receives Medicaid LTSS come from?

Who Receives Medicaid LTSS?

- Transformed Medicaid Statistical Information System ([T-MSIS](#)), 2021
- State-reported Medicaid claims data
- Population of adult Medicaid beneficiaries



Race and Ethnicity Data Quality Assessment among Adults Receiving Medicaid HCBS



How do we define who receives Medicaid LTSS using the T-MSIS data? [CMS method]

Home and Community-Based Services (HCBS):

- Section 1915(c) Waiver, Section 1915(i) HCBS State Plan Option, Section 1915(j) Self-Directed Personal Assistance Services, Section 1915(k) Community First Choice, PACE, Personal Care Services, Home Health, Rehabilitation Services, Case Management, & Private Duty Nursing Services

Institutional LTSS:

- Nursing Facilities, Mental Health Facilities, & Intermediate Care Facilities for Individuals with Intellectual Disabilities

How many adults need LTSS versus how many adults receive Medicaid LTSS?

Who Needs LTSS?

- 17.6 million adults (6.8% of adult U.S. population)

Who Receives Medicaid LTSS?

- 6.4 million adults (10.7% of adult Medicaid beneficiaries)*

*Alabama and Mississippi are excluded due to data quality concerns.

Why is there a difference between who needs LTSS and who receives Medicaid LTSS?

- Not everyone who needs LTSS qualifies for Medicaid LTSS
- Some people receive LTSS through alternative sources:
 - Medicare (acute/post-acute care)
 - Private insurance
 - Out-of-pocket
 - Informal/unpaid
- Unmet LTSS needs



Community Living Data Dashboard Demonstration

[Link to the dashboard homepage](#)

Q & A

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