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THE HELLER SCHOOL
FOR SOCIAL POLICY
AND MANAGEMENT
Lurie Institute
for Disability Policy

ADA30: Addressing Barriers to the ADA's Right to Community Participation

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Introductions

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Americans with Disabilities Act

“...the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals.”

Olmstead v. L.C.

Lois Curtis & Elaine Wilson

Affirmed that the ADA provides a right to live & receive support in the community.



ADA 30: where are we now?

- The ADA provides a right to live in the community--***but not the services necessary to make that right a reality.***
- Home and Community-Based Services (HCBS) are provided through Medicaid.
- Medicaid and the ADA are not in alignment.
- As a result, hundreds of thousands of people with disabilities are still trapped in institutions.

Long-Term Services and Supports

What are LTSS?

- Broad range of services and supports that assist individuals who have long-term functional needs with daily living

Who needs LTSS?

- Currently about 12 million Americans
- Half under 65 years of age
- Number will more than double to from 12 to 27 million by 2050

Who pays for LTSS?

- Medicaid is the primary payer
- Medicare generally **does not cover**

Institutional Bias within Medicaid

Nursing homes are **mandatory** within Medicaid, while Home and Community-Based Services (HCBS) are **optional**

- States can limit availability of HCBS
- Services vary considerably from state to state
- In many states, long waiting lists for HCBS
- Forces people into more costly, undesirable nursing homes and other institutions

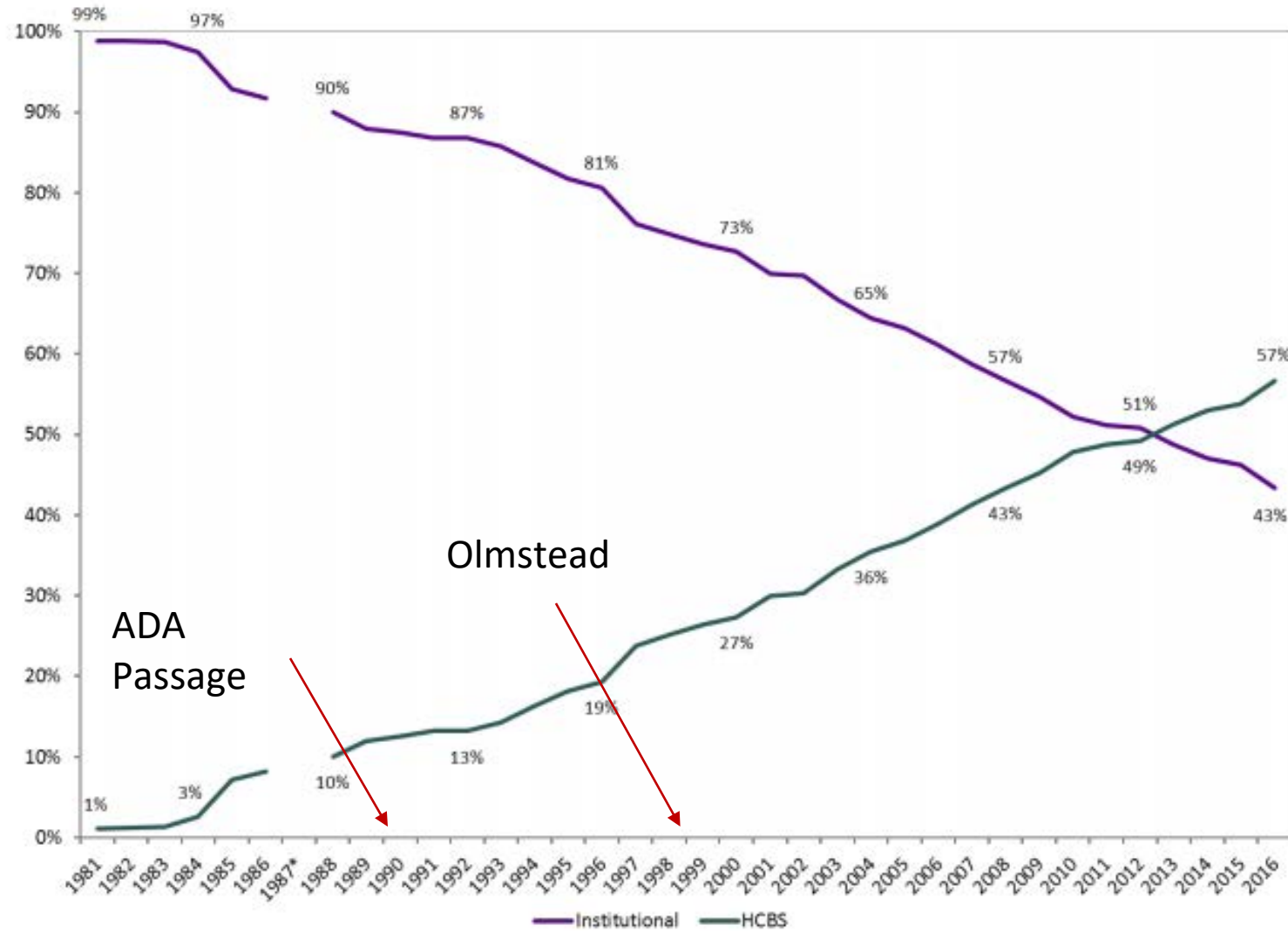


“Rebalancing” LTSS Service Systems

Significant progress has been made over the past several decades in **shifting from institutional to Home and Community-Based Services**

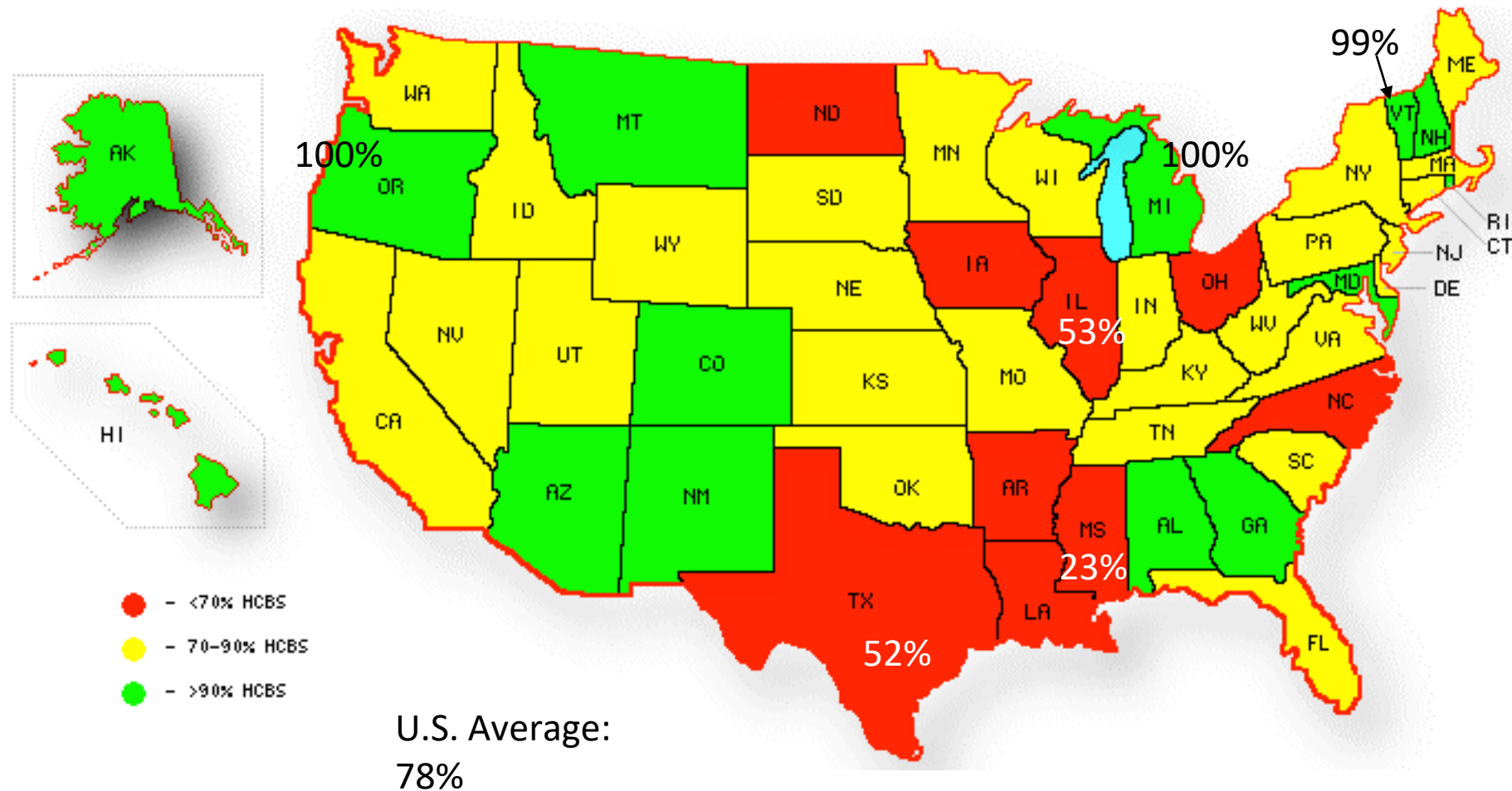
- 1999 Olmstead Decision
 - Unjustified segregation is a violation of the Americans with Disabilities Act
- Federal programs and incentives have assisted states with rebalancing



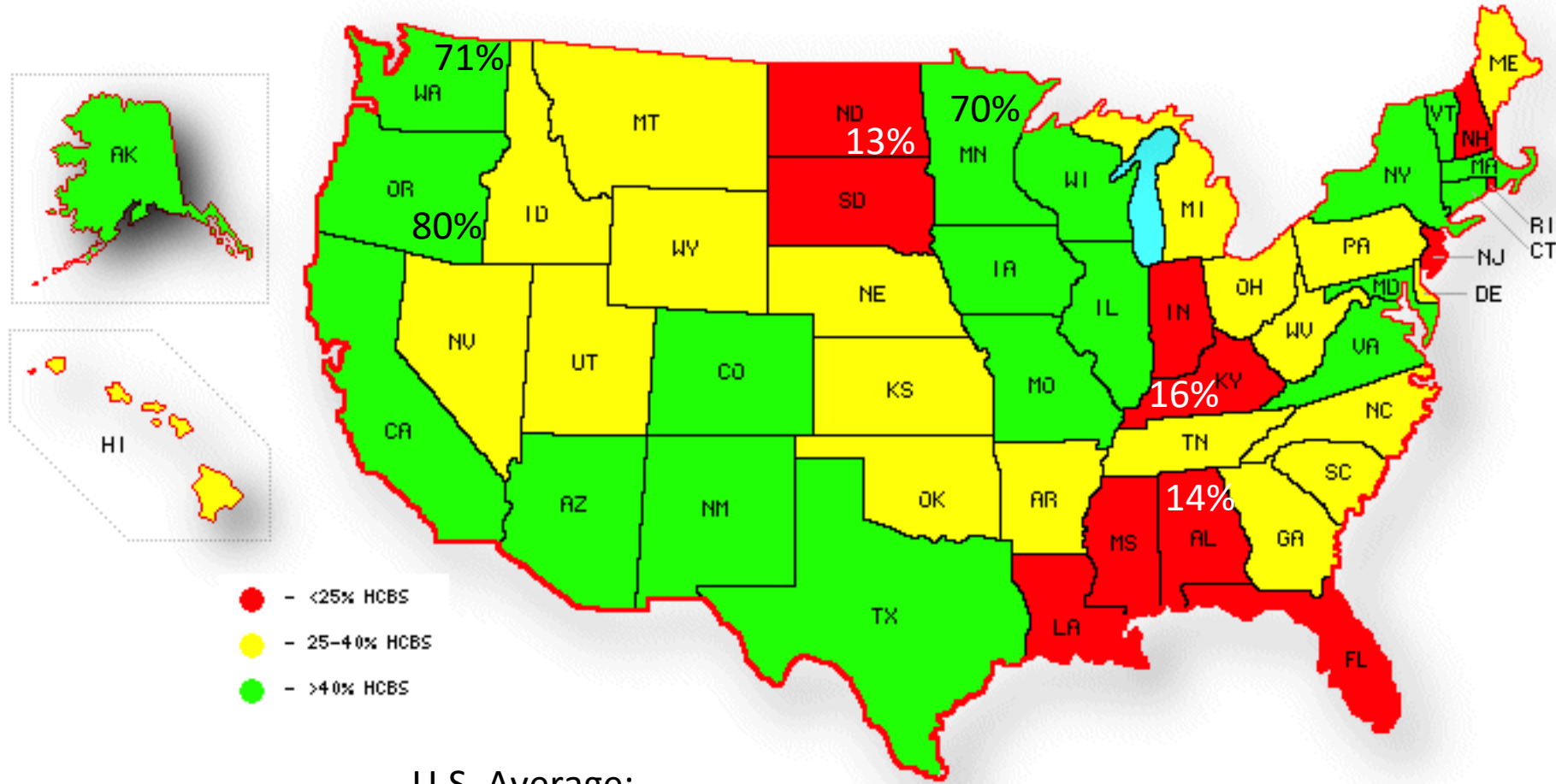


Percentage of Total Medicaid LTSS Spending on HCBS, 1981-2016

Proportion of I/DD Medicaid LTSS spending devoted to HCBS



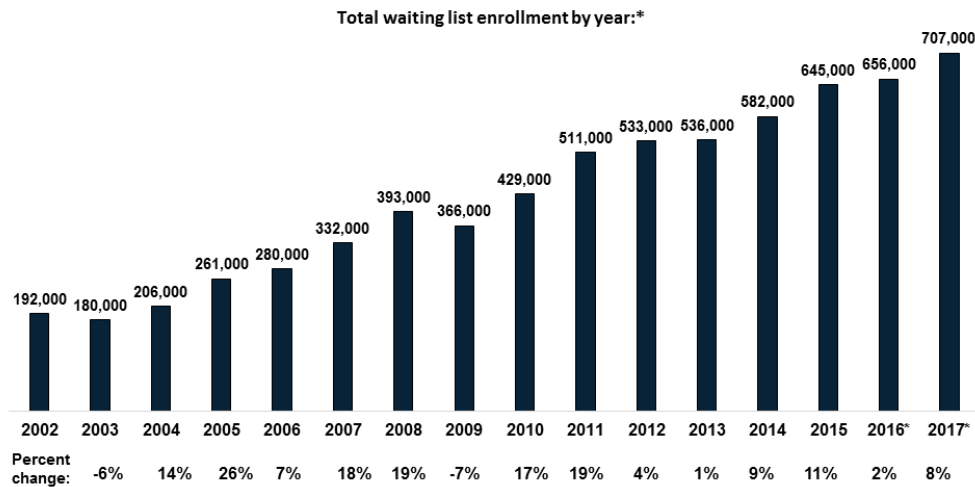
Proportion of Non-I/DD Medicaid LTSS spending devoted to HCBS



U.S. Average:
46%

Growing Waiting Lists for HCBS

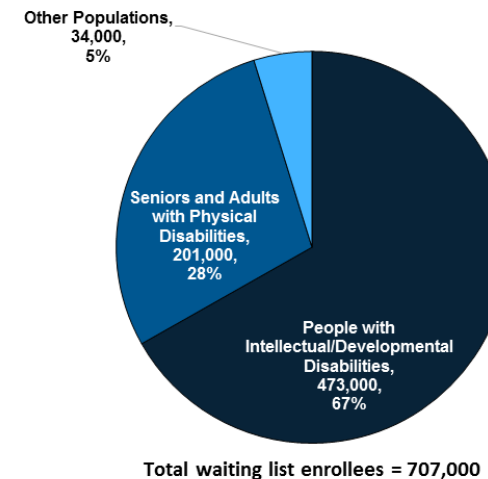
Figure 1
Medicaid HCBS waiver waiting list enrollment, 2002-2017.



NOTES: Percent change is calculated using unrounded totals. *Beginning in 2016, totals include Section 1916 (c) and Section 1115 HCBS waiver waiting lists except that CA and NY did not report enrollment for Section 1115 waiting lists; prior years include only Section 1915 (c) waiver waiting lists.
SOURCE: Kaiser Family Foundation Medicaid FY 2002-2017 HCBS program surveys.



Figure 2
Medicaid HCBS waiver waiting list enrollment, by target population, 2017.



NOTES: Numbers may not sum to totals due to rounding. Data include Section 1915 (c) and Section 1115 HCBS waiver waiting lists except that CA and NY did not report Section 1115 waiting list enrollment, and AL reports its Section 1915 (c) IDD waiting list as "unknown." Other Populations include children who are medically fragile or technology dependent, people with HIV/AIDS, people with mental health needs, and people with traumatic brain or spinal cord injuries. SOURCE: Kaiser Family Foundation Medicaid FY 2017 HCBS program survey conducted in 2018.



The Impact of COVID-19 on People with LTSS Needs: Institutional Settings

- Over **40% of all US coronavirus deaths** have been in nursing homes
- **African Americans are more likely to die from COVID-19 in nursing homes** than their white counterparts
- **30% of people with intellectual disabilities** in the US live in group homes, supported-living apartments, or large-scale state institutions.
- **Institutional settings are often short-staffed** and can't provide high-risk residents appropriate care
- Triaging protocols deprioritize people with IDD, especially in institutions



Courtesy of Lauren A. Little, Getty Images

Olga Khazan, "Another Coronavirus Nursing-Home Disaster Is Coming." *The Atlantic*,

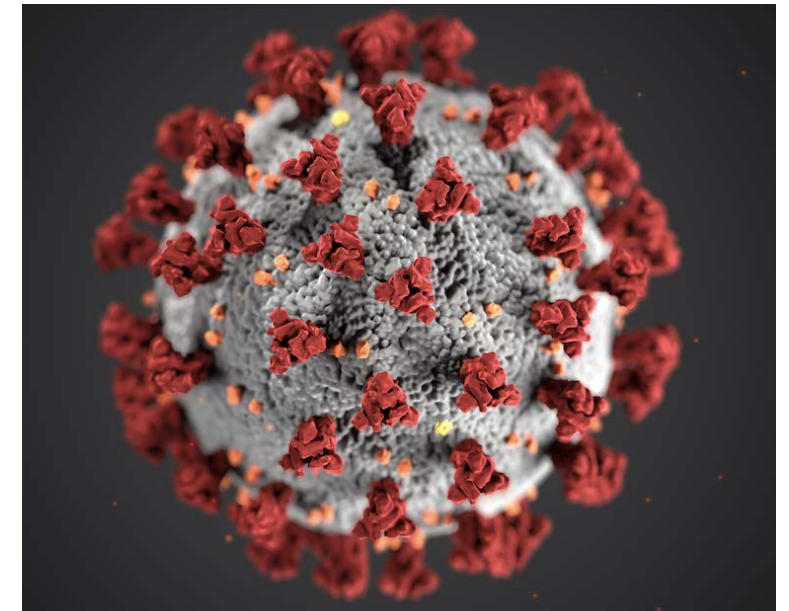
6 July 2020. <https://www.theatlantic.com/health/archive/2020/07/us-repeating-deadliest-pandemic-mistake-nursing-home-deaths/613855/>;

Jane Coaston, "We're being punished again: How people with intellectual disabilities are experiencing the pandemic." *Vox*, 9 April 2020. Frank Main, "University of Chicago's Tamara

Konetzka on COVID-19." *Chicago Sun-Times*, 21 May 2020. <https://chicago.suntimes.com/2020/5/21/21266422/tamara-konetzka-nursing-homes-coronavirus-senate-special-subcommittee-agin-university-of-chicago>

The Impact of COVID-19 on People with LTSS Needs: Institutional Settings

- Nursing homes with the lowest percentage of white residents were more likely to have coronavirus cases or deaths
- Problems contributing to higher coronavirus risk: congregate living, lack of sanitation training, understaffing, lack of benefits for staff



Courtesy of the Centers for Disease Control

Olga Khazan, “Another Coronavirus Nursing-Home Disaster Is Coming.” *The Atlantic*,

6 July 2020. <https://www.theatlantic.com/health/archive/2020/07/us-repeating-deadliest-pandemic-mistake-nursing-home-deaths/613855/>;

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The Impact of COVID-19 on People with LTSS Needs: Racial Disparities

- In some states, the Black COVID-19 death rate is 4-6 times as high as it is for white people
- Racial disparities in housing, employment, and health care reduce people's ability to withstand the effects of a COVID-19 infection



Courtesy of John Moore, Getty Images

Claudia Walls, "Why Racism, Not Race, Is a Risk Factor for Dying of COVID-19." *Scientific American*, 12 June 2020.

The Impact of COVID-19 on People with LTSS Needs: Racial Disparities

- Black and Asian Americans have encountered higher rates of ostracism and suspicion since the beginning of the COVID-19 pandemic
- Black Americans are more likely to be hospitalized for COVID-19-related symptoms

Asian and Black Americans more likely than other groups to report negative experiences because of their race or ethnicity since the coronavirus outbreak

% saying each of the following has happened to them because of their race or ethnicity since the coronavirus outbreak



% saying they _____ because of their race or ethnicity a great deal or a fair amount



*Asian adults were interviewed in English only.
Note: White, Black and Asian adults include those who report being only one race and are not Hispanic. Hispanics are of any race.
Source: Survey of U.S. adults conducted June 4-10, 2020.
"Many Black and Asian Americans Say They Have Experienced Discrimination Amid the COVID-19 Outbreak"

PEW RESEARCH CENTER

Neil G. Ruiz, Juliana Menasce Horowitz, and Christine Tamir, "Many Black and Asian Americans Say They Have Experienced Discrimination Amid the COVID-19 Outbreak." Pew Research Center, 1 July 2020. <https://www.pewsocialtrends.org/2020/07/01/many-black-and-asian-americans-say-they-have-experienced-discrimination-amid-the-covid-19-outbreak/>

Marie Killerby, et al., "Characteristics Associated with Hospitalization Among Patients with COVID-19 — Metropolitan Atlanta, Georgia, March–April 2020." Centers for Disease Control, 26 June 2020.

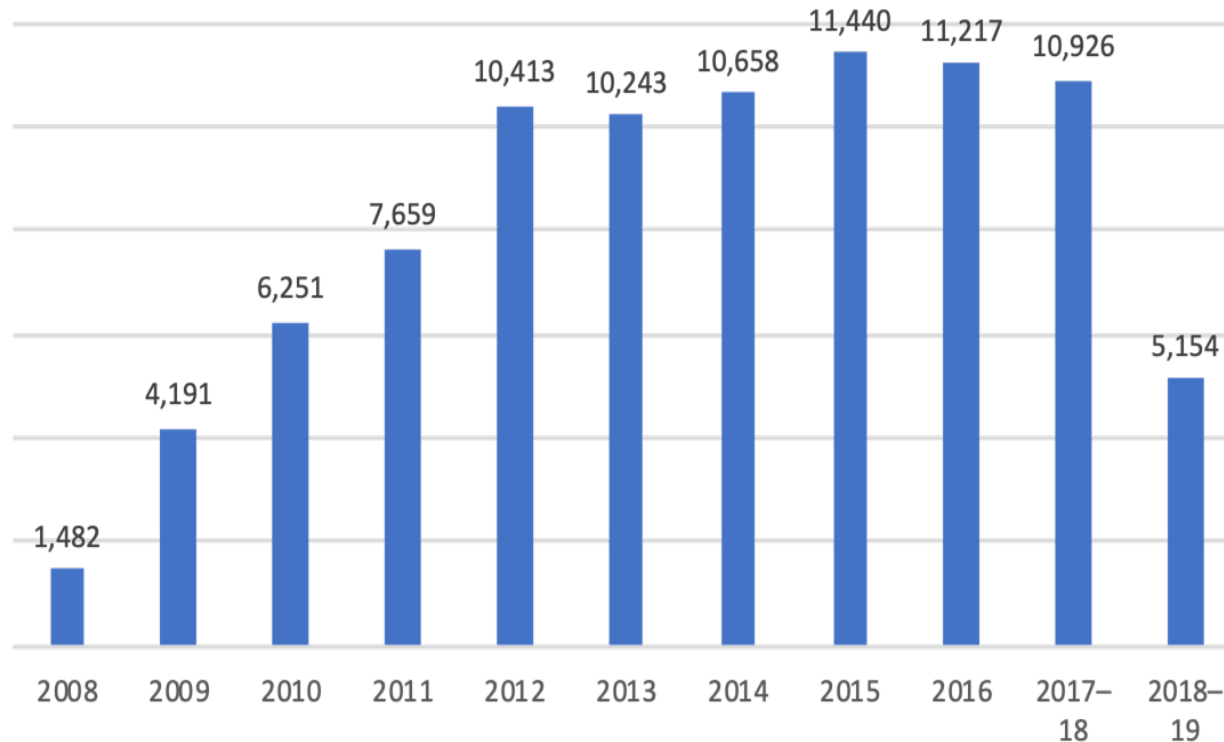
Policy Solutions

Money Follows the Person (MFP)

- Long-standing Medicaid demonstration program:
 - First authorized in 2005
 - Assists states with transitioning people who want to move back home from nursing facilities and other institutions
 - Independent evaluation has demonstrated improvements in quality of life after transitioning to the community, including:
 - Increases in life satisfaction, satisfaction with living arrangements, satisfaction with care received, and community integration.
 - One year after transitioning to the community, approximately 9 percent of participants reported volunteering in the community and 7 percent reported working for pay.
- Congress has passed five short-term extensions of the program
- Program is set to expire again November 30, 2020

MFP Transitions

Annual Money Follows the Person transitions, 2008–2019



Over 91,540 people have moved from institutions back to their home through the program

However, short term extensions have led to a drop off in transitions

Making the program permanent would provide greater certainty for states and strengthen the program

Other Legislation

- Dedicated HCBS funding for COVID-19
- HCBS Infrastructure Improvement Act (S. 3277)
 - Would provide grants to states to help build infrastructure to support home and community-based services (including housing, transportation, workforce and unpaid caregiver needs, employment supports, no wrong door/single entry point system).

Community Living Policy Center

- National center that conducts research, training, and technical assistance
- Aims to advance policies and practices that promote community living outcomes for people with disabilities of all ages

www.commmunitylivingpolicy.org
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