

**From New Jersey to Nationwide:
Leveraging Lessons Learned to
Advance the Promise of
Olmstead for Older Adults and
People with Disabilities**

Long Term Care Community Coalition
January 2024



ADVANCING JUSTICE. ADVOCATING INCLUSION.



Agenda for Session

- Intro and Background on Key Federal Laws
- DRNJ's Person First Investigation and Recommendations:
 - People with IDD in New Jersey Nursing Homes
- NJ's LTC Ombudsman's Perspective from the Frontline:
 - New Jersey's Pilot Behavioral Health Units in Nursing Homes
- Justice in Aging: Inequities in HCBS & an Equity Framework in HCBS
- Q&As



Setting Stage for Discussion

- Olmstead: Title II of Americans with Disabilities Act (ADA)
- Federal HCBS Settings Rule: Person-Centered Planning
- Section 504 of the Rehabilitation Act



Olmstead and the ADA: Nursing Homes

- Held: Unjustified segregation and isolation of people with disabilities, particularly in institutions, by state is discrimination in violation of Title II of the Americans with Disabilities Act
- Held: State must provide services and supports to people with disabilities in the most integrated setting appropriate to needs of individual
- Held: Settings must enable people with disabilities “to interact with non-disabled persons to the fullest extent possible.”
- Olmstead Requirements: Applies to nursing homes



HCBS Settings Rule & Person-Centered Planning

- 2014: Person-Centered Planning Rights in effect
 - Planning Process
 - Written Plan
 - Review of the Person-Centered Service Plan
- 2023 March: Implementation of Settings Portion of the Rule
 - Established minimum standards to ensure truly non-institutional settings
 - Ensure that HCBS residents have same access to community
 - Provider-owned or controlled settings: additional conditions
 - Special Concern: Eviction and due process protections for residents
- 2016: Revised Nursing Home Regulations



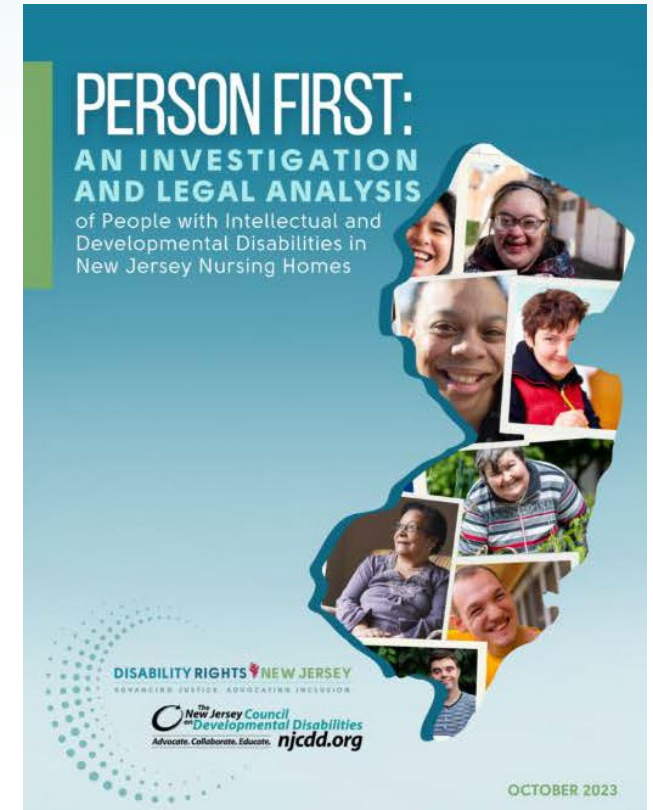
Section 504 of the Rehabilitation Act of 1973

- First civil rights legislation protecting disabled people from discrimination
- Prohibits discrimination on the basis of disability in “any program or activity receiving federal financial assistance”
- Proposed updates to the current rule (open now for public comment) clarify obligations in several crucial areas and improve consistency with legislative developments since regulations were issued
 - **Community integration:** The proposed rule incorporates language reflecting the principles established in *Olmstead v. LC* to clarify obligations to provide services in the most integrated setting appropriate to a person’s needs



Person First: Investigation

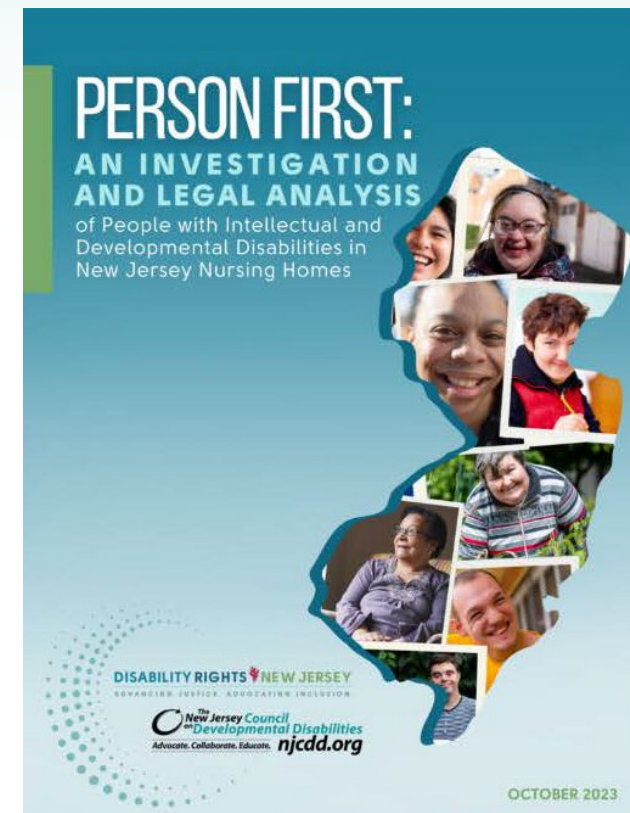
- NJ's designated Protection and Advocacy agency
- Federal authority to monitor and investigate allegations of abuse and neglect – including in nursing facilities
- Long Term Care Ombudsmen have similar authority as it related to nursing facilities





Person First: Investigation

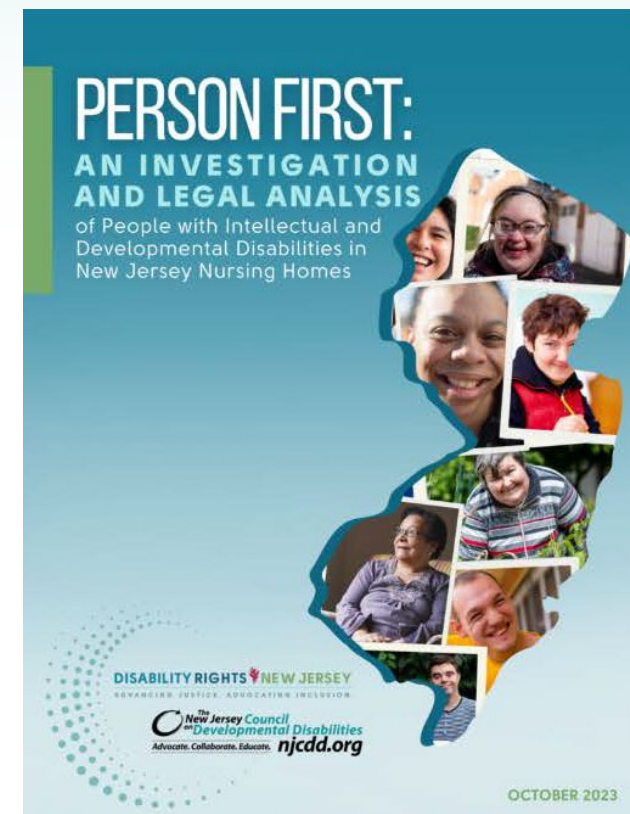
- Concerns about people with IDD in nursing homes before the pandemic
- COVID-19 pandemic illustrated how awful the situation was for all nursing home residents, but particularly those with disabilities
- Disability Rights NJ launched formal investigation in early 2022





Person First: Investigation

- List from state: 600 people
- Visited 70 nursing facilities, 1 pediatric facility
- Visited with 357 people with IDD
- Visited at least 50% of the population in each county
- Collected face sheets, PASRRs, and guardian information
- Spoke with guardians and stakeholders

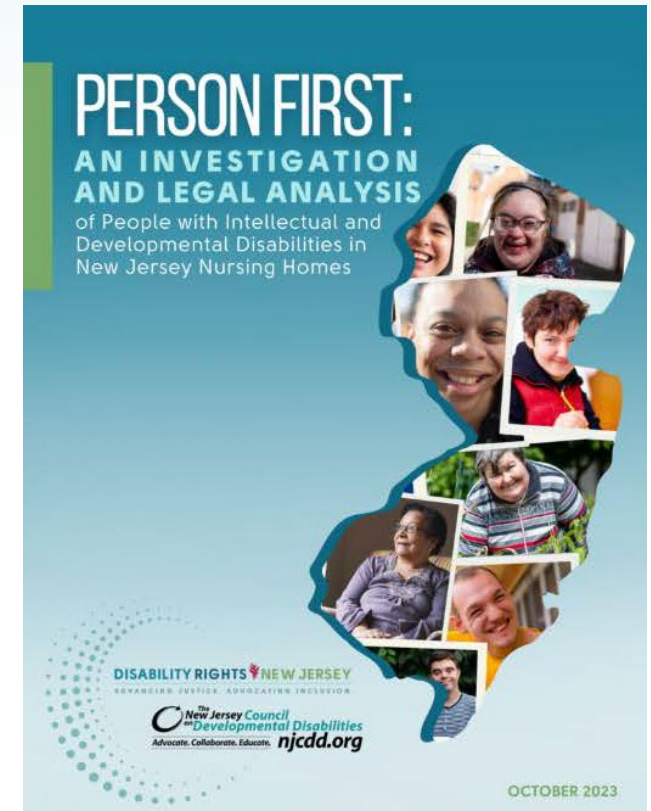




Person First: Key Finding One

Key Finding One: The State of New Jersey does not have an accurate count of the number of people with IDD living in nursing homes, nor does it have important information about those people.

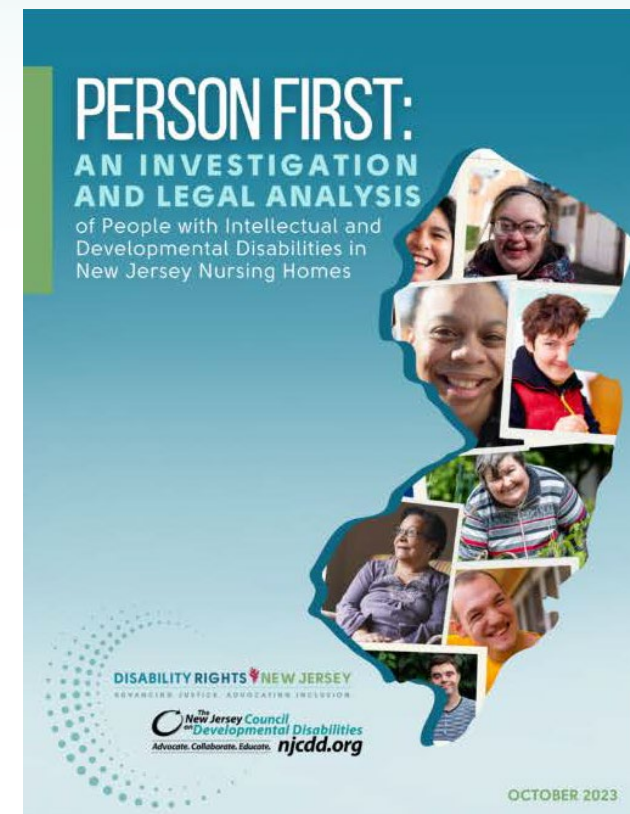
- State data: 600 people with IDD in NJ nursing homes and PASRR data
- Federal MDS data: Numbers higher than what was reported by DDD





Person First: Key Finding One Recommendations

- NJ should maintain a cross-agency, data collection of individuals with IDD in nursing homes – including demographic information
- NJ should maintain a public dashboard with non-identifiable information about people with IDD in nursing homes
- NJ should monitor and analyze available MDS data around individuals with IDD in nursing homes

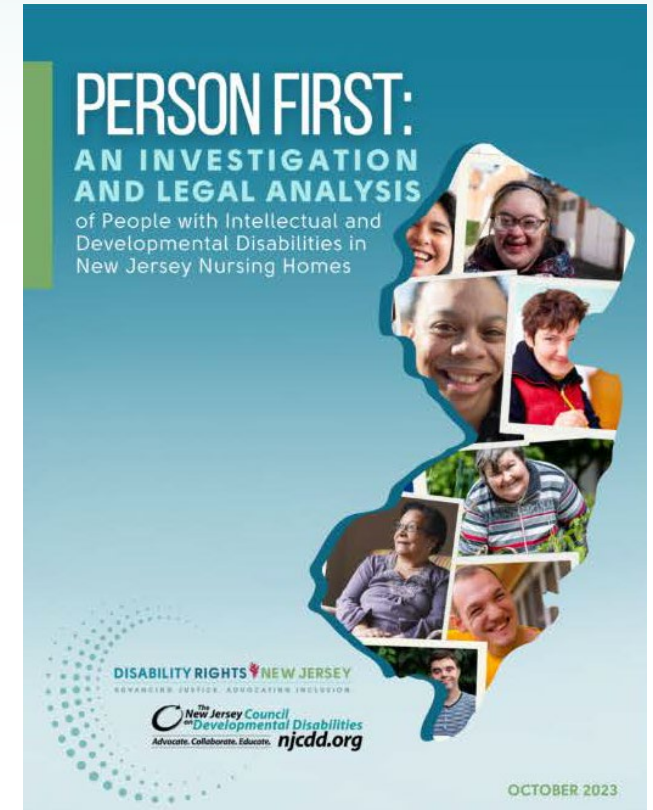




Person First: Key Finding Two

New Jersey's PASRR system is irrevocably broken: it is out of compliance with federal law and it is not functioning as a powerful Olmstead tool to divert and transition people with IDD and mental health disabilities from nursing homes to the most integrated appropriate settings with needed services and supports.

- NJ's PASRR process does not comply with federal law
- Overview of NJ's PASRR process
 - Definition of specialized services in NJ
 - Categorical determinations
- PASRR as an Olmstead tool

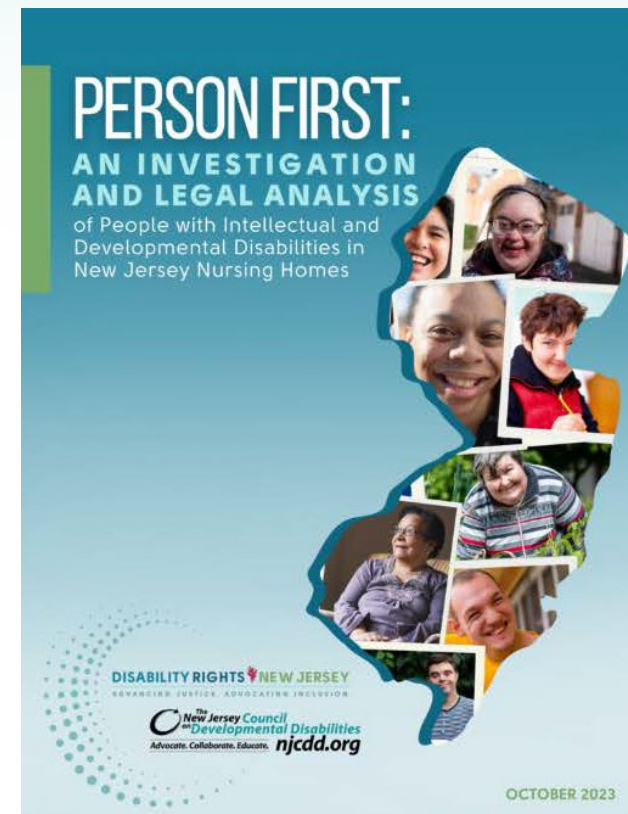




Person First: Key Finding Two Recommendations

- NJ should review the State's implementation of the PASRR process and revise to comply with federal law with focus as powerful *Olmstead* tool
 - Key stakeholders, family members, and individuals with IDD should partake in this revision process
- NJ should redesign the PASRR process with a person-centered framework
- NJ should amend the definition of specialized services to comply with federal law

All entities utilizing PASRR should receive training on these revisions once implemented

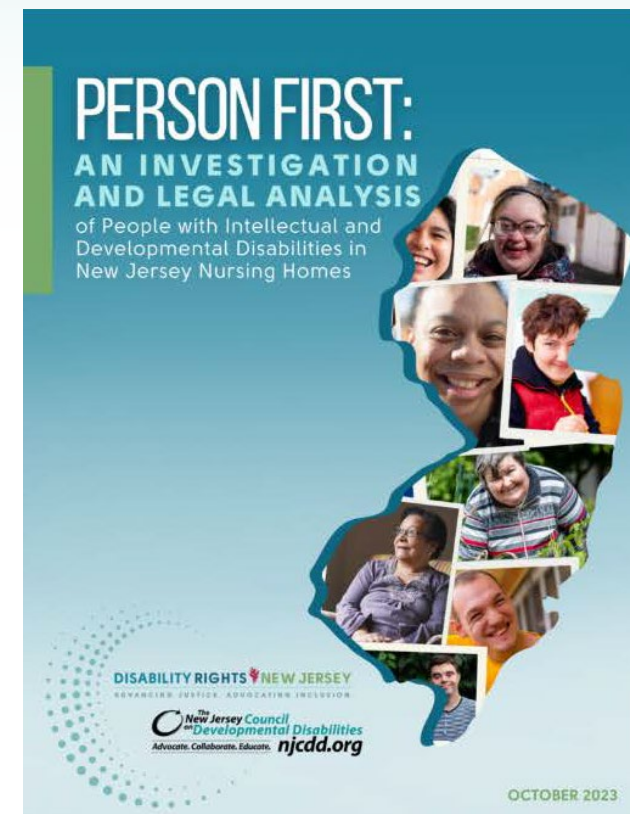




Person First: Key Finding Three

Throughout the State, people with IDD are not afforded their constitutionally protected right to self-determination regarding where they live, nor are they afforded meaningful opportunities to engage in federally mandated person-centered practices. As a result, people with IDD are forced into nursing homes and are thus denied interactions with non-disabled people: a choice of one – a nursing home – is not a choice.

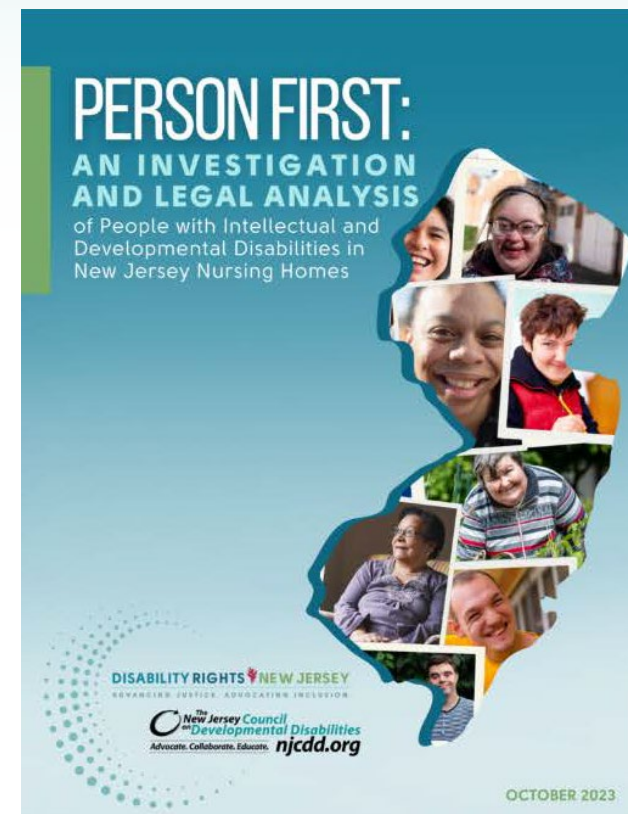
- Individuals with IDD have a fundamental right to self-determination
- Federal person-centered planning rights: nursing homes and HCBS
- Housing barriers in NJ and HCBS Settings Rule protections





Person First: Key Finding Three Recommendations

- NJ should review person-centered rights and practices throughout the long-term services and supports system to comply with federal law and individual rights
- NJ should review and revise service plans and planning processes to ensure they are consistent with federal requirements for person-centered practices
- NJ's DDD should dedicate a team to work with individuals with IDD in nursing homes who want to return to the community





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New Jersey Office of the Long-Term Care Ombudsman

Amy Brown
Director of Policy

Rise in Nursing Home Residents with Mental Health Challenges

- Increase in residents with mental health diagnoses
- Younger residents
- Formerly unhoused residents
- Formerly incarcerated residents
- Do not need traditional NH care (or very minimal) but do need MH-related services/supports
- Statewide lack of affordable supportive housing

DRNJ Report Just as Applicable to Mental Health Population

- Improper institutionalization (often related to housing need)
- Lack of specialized services (PASRR)
- Lack of person-centered planning and care
- Inadequate staff training to properly care for this population.

Intermediate Behavioral Health NF Units (new, 2022) – Origins and Concerns

- History:
 - 2 Intermediate behavioral units created by NJ DOH in 2022 when large nursing home housing people with disabilities closed
 - Substantial need for Woodland residents didn't materialize but other residents being sent there
 - Licensure requirements but no regulations
- Concerns:
 - Resident placement / not cycling out when ready
 - Availability of required therapies
 - Resident population mix
 - Integration w/ larger nursing home
 - Olmstead and Constitutional concerns

LTCO Advocacy for Residents of Intermediate Behavioral Health Units

- Help residents move off of these units.
- Collaborate w/ MCO care managers to routinely visit and assess their members.
- Insist residents have the right to outdoor time and meaningful and appropriate recreation.
- Ensure therapies are occurring.
- Advocate that residents be able to leave the unit and integrated within the community itself.
- Ensure residents' other basic needs are met.
- Speak with guardians to relay resident wishes and goals.

Future of Advocacy for Residents with Mental Health Challenges in Nursing Homes

- Create more supportive housing
- Eliminate institutional bias / strengthen HCBS
- Ensure PASR-R process working as intended/required
- Ensure residents receive needed specialized services
- More robust training for care staff re mental health
- Increase staffing to ensure highest level of functioning for MH population

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JUSTICE IN AGING

FIGHTING SENIOR POVERTY THROUGH LAW

From New Jersey to Nationwide: Leveraging Lessons Learned to Advance the Promise of Olmstead for Older Adults and People with Disabilities

Hannah Diamond, Policy Advocate

January 23rd, 2024

JUSTICE IN AGING

FIGHTING SENIOR POVERTY THROUGH LAW

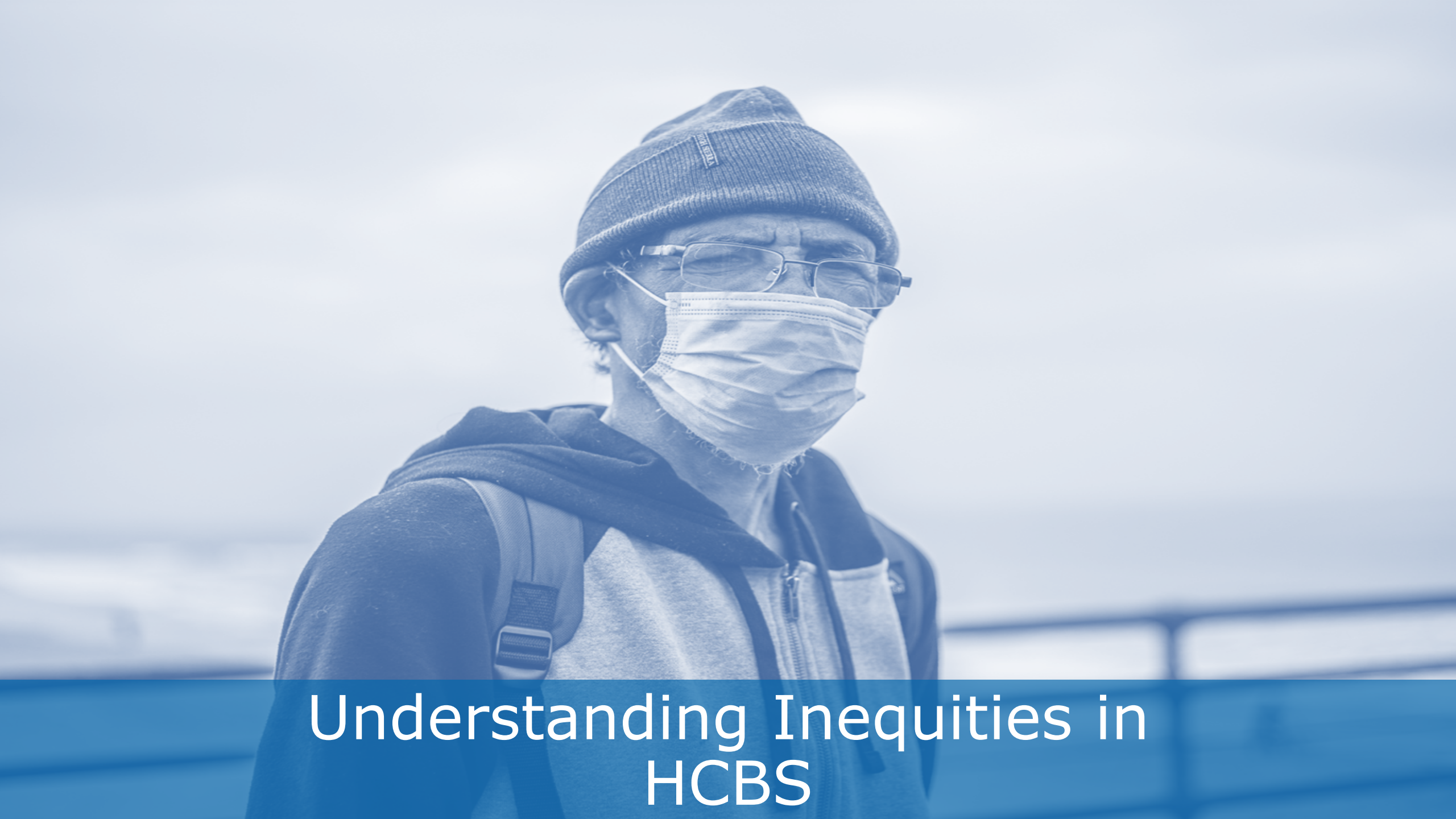
Justice in Aging is a national organization that uses the power of law to fight senior poverty by securing access to affordable health care, economic security, and the courts for older adults with limited resources.

Since 1972 we've focused our efforts primarily on fighting for people who have been marginalized and excluded from justice, such as women, people of color, LGBTQ+ individuals, and people with limited English proficiency.

Justice in Aging's Commitment to Advancing Equity

To achieve Justice in Aging, we must:

- [Advance equity](#) for low-income older adults in economic security, health care, housing, and elder justice initiatives.
- Address the enduring harms and inequities caused by systemic racism and other forms of discrimination that uniquely impact low-income older adults in marginalized communities.
- Recruit, support, and retain a diverse staff and board, including race, ethnicity, gender, gender identity and presentation, sexual orientation, disability, age, and economic class.



Understanding Inequities in HCBS

Institutional Bias Limits Access to HCBS

- Federal Medicaid law requires states to cover institutional long-term care, but it does not require states to provide the full range of HCBS that people need
 - Someone needing long-term care is only guaranteed services in a nursing facility
 - Shift to less institutional and more integrated long-term care led to an increase in HCBS programs
- *Olmstead v. LC* decided that the unnecessary institutionalization of individuals living with disabilities violates their rights under the ADA to receive services in the least restrictive setting

Opportunities to Improve Equity in New Jersey's HCBS

- Across all populations, New Jersey is ranked 35th nationally for rebalancing the provision of care from institutional to HCBS settings
- When LTSS expenditures are stratified by population, disparities become more prevalent
 - Just 21% of New Jersey's Medicaid LTSS spending went towards HCBS for older adults and people with physical disabilities



Medicaid HCBS for Older Adults in NJ

Demographic Info of Dual Eligibles in NJ

New Jersey is home to 220,000 low-income older adults who are dually eligible for Medicare and Medicaid

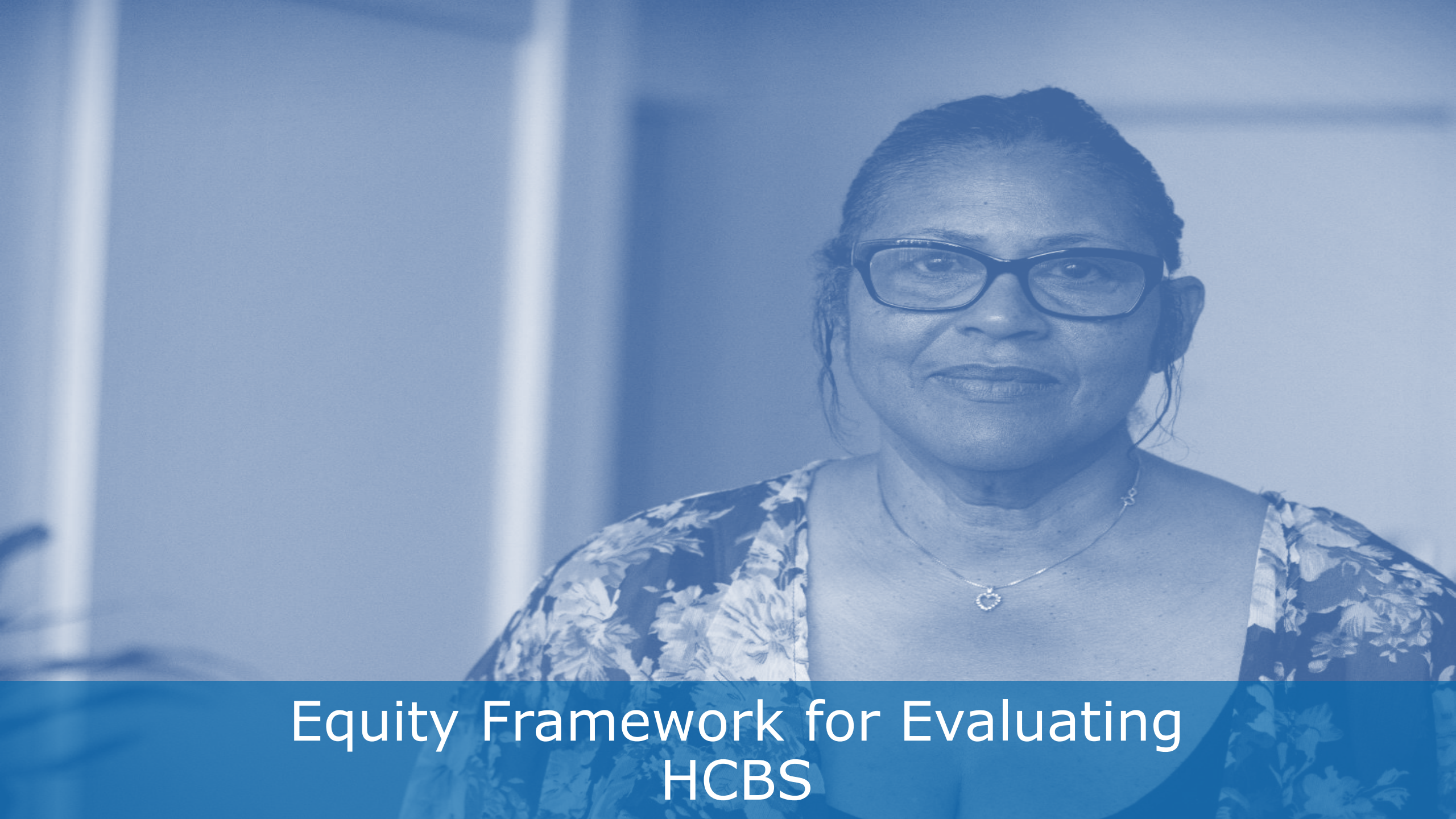
Dually Eligible	Medicare-Only
44% White	79% White
21% Black	9% Black
9% Hispanic	3% Hispanic
24% Asian or Pacific Islander	6% Asian American or Pacific Islander

How New Jersey FamilyCare Provides LTSS

- New Jersey State Plan LTSS Benefits include:
 - Medical benefits
 - Home health care, medical day care, personal care assistant services
 - Various eligibility pathways, including SSI and Medicaid Only
 - Strict income and asset limits

NJ Family Care MLTSS

- MLTSS benefits offered beyond State Plan benefits provided by a managed care organization (MCO)
- Must meet clinical and financial eligibility criteria



Equity Framework for Evaluating HCBS

Centering Equity in HCBS Design

Drivers of inequity:

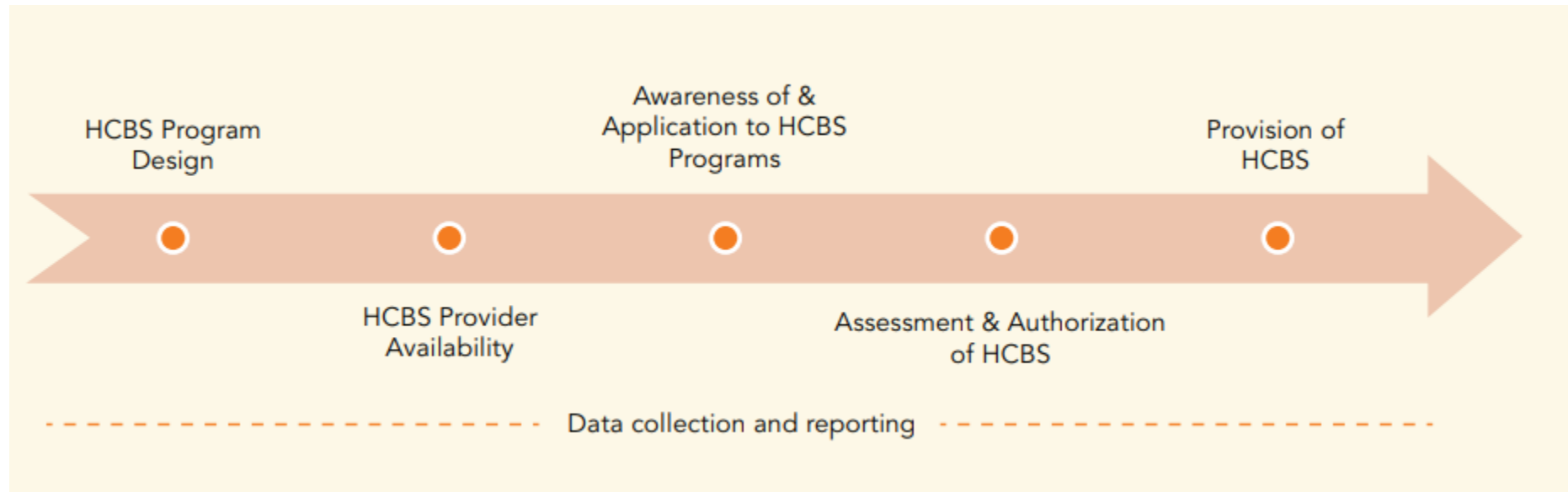
- Racism
- Ageism
- Ableism
- Classism
- Sexism
- Xenophobia
- Homophobia

Embedded in law, program policy, design and implementation:

- Structural and historical barriers
- Disparate Impact
- Implicit Bias

HCBS Equity Framework

- A tool to center equity by examining how a program's design or policy impacts specific people and populations
 - E.g., Older adults, people of color, native populations, women, LGBTQ+ individuals, people with limited English proficiency, people in urban or rural settings
- A starting point for advocates & policy makers



Five Domains Where Inequities Arise in HCBS

1. Program Design
 - Who is eligible, where programs are available, what services are offered
2. Provider Availability
 - Network adequacy, reimbursement rates, investments training & support
3. Program Awareness and Enrollment
 - Communication, information and application processes
4. Assessments and Authorization of Services
 - How bias in the process impacts who gets approved
5. Provision of HCBS
 - Person-centered service accessibility and quality measures

Note: Data collection and reporting are key to transparency and oversight across all domains

1. Program Design

- Medicaid Authority
 - Is the program available statewide or only in certain regions?
 - Do all populations have access or is a program limited to older adults or people with intellectual/development disabilities?
 - Is there a cap on enrollment?
 - Does the waiver authority limit the level of care criteria for who can participate?
- Community Engagement
 - Were people with lived experiences consulted and engaged?
- Program Benefits
 - Which services are included or excluded?
- Waiver Waitlist Administration
 - Is there a waitlist?
 - What are the processes/barriers to getting on the waitlist and advancing?

Equity Evaluation of Program Design: Income Limits for NJ State Plan Benefits

- Income eligibility criteria to access NJ State Plan benefits are inequitable
 - Older adults and people with disabilities
 - Income limits of 100% FPL or \$1,215 in 2023
 - Single adults under age 65
 - Income limits of 138% FPL or \$1,677 in 2023

Asset Limits

- Differs depending on NJ FamilyCare Program
 - Age, Blind, Disabled: \$4,000
 - MLTSS: \$2,000
 - Medicare Savings Programs: \$9,090
 - Single adults under age 65: No asset limits
- Older adults and people with disabilities experience more stringent income and asset criteria than other Medicaid populations

2. Provider Availability

- Network Adequacy Standards
 - Does the state have network adequacy standards for HCBS?
 - Do standards maintain the status quo or perpetuate racial segregation? Are individuals' actual needs incorporated?
- HCBS Provider Reimbursement Rates
 - Are state reimbursement rates high enough to maintain an adequate workforce, especially in areas with high cost of living or rural locations?
 - Are underserved areas growing?
- Caregiver Supports
 - Which caregivers know about these supports? Do they meet the diverse needs of unpaid caregivers?

Equity Evaluation of Provider Availability: NJ Example

- New Jersey's Assisted Living Residence (ALR) program is one way residences can access assisted living benefits
- 6 counties in New Jersey have the most older residents
 - Bergen, Middlesex, and Essex: more racially diverse
 - Ocean, Monmouth, and Morris: less racially diverse
- The more racially diverse counties have fewer ALR facilities
 - 24 ALR facilities in Bergen, Middlesex, and Essex counties
 - 51 ALR facilities in Ocean, Monmouth, and Morris counties
- Data demonstrates that provider availability is inadequate in the state's most populous and racially diverse counties
 - Consistent with research findings that assisted living facilities are located disproportionately in higher income and less racially diverse counties

3. Program Awareness and Enrollment

- HCBS Program Information
 - Is information centralized and searchable?
 - Can people who don't know the HCBS system find this information?
- Education by Enrollment Entities
 - Are states and programs doing outreach? To whom?
 - Is the information entities provide consistent and accurate about who is eligible?
- HCBS Application Forms
 - Are the application forms easy to find and accessible to people with disabilities or limited English proficiency?
 - Can someone fill out the form and navigate the application process by themselves?
 - Is help with application forms readily available?

Equity Evaluation of Program Awareness and Enrollment: New Jersey Example

- Stakeholders report that the application process to apply for HCBS in New Jersey is complex and that many resources are only available online
- Targeted strategies regarding education and outreach must prioritize unhoused populations, those with limited English proficiency, and communities of color
 - Black and Latino older adults less likely to know about the PACE program

4. Assessments and Authorization of Services

- Assessment tools & assessors
 - Are implicit and explicit biases impacting eligibility determinations and assessments?
- HCBS “Level of Care” Evaluations
 - Are people with certain types of disabilities less likely to be determined eligible?
- HCBS Needs Assessments
 - Are there differences by population, disability, race, etc. in the types and level of services a person is assessed as needing?
 - Does the assessment appropriately account for the individual’s situation and preferences?

Equity Evaluation of Authorization of Services: New Jersey Example

- Money Follows the Person Program (MFP)
 - Helps adults with disabilities of all ages move out of institutions and into the community
 - New Jersey's MFP, I Choose Home, has completed 3,229 cumulative transitions
 - Data demonstrates that transitions are disproportionate across populations
 - People age 65+ receive MFP at disproportionately lower rates than younger people
 - 1116 of 3,229 were transitions of older adults (approx. 1/3)
 - However, older adults make up a higher proportion of individuals residing in nursing facilities (approx. 78% of NJ MLTSS nursing facility residents are 65 years and older)

5. Provision of HCBS

- Adequacy and quality of services provided
 - Are the adequacy and quality of services being monitored and measured?
 - Are their grievance processes and other enforcement mechanisms?
- HCBS Quality Measures
 - Do quality measures include demographic data to measure disparities for marginalized communities?
- Language Access
 - Can HCBS participants communicate with their providers?
 - Are language resources, including translated information about the program and services provided?
- Cultural Competence & Humility
 - Are providers ensuring direct care workers receive cultural competency training to serve LGBTQ+ individuals and other marginalized communities?
 - Do states require providers to deliver services in a culturally appropriate manner?

Equity Evaluation of HCBS Provision Example

- Serving LGBTQ+ Older Adults
 - LGBTQ+ individuals often face discrimination in long-term care settings and many report not being comfortable sharing their LGBTQ+ identity with their caregivers
 - HCBS providers typically are not required to complete LGBTQ+ training
 - Limits provider choice
 - Impacts service quality
 - Risks discrimination and harm

Resources

- An Equity Framework for Evaluating and Improving Home and Community-Based Services
 - [Issue Brief](#)
 - [Fact Sheet](#)
- [HCBS Primer](#)
- [HCBS 101 Webinar](#)
- [22 Recommendations to Improve Equitable Access to HCBS in NJ](#)
- [Fact Sheet on How to Raise the Medicaid Income Limits for Older Adults and People with Disabilities in NJ](#)



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Questions?

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