

Disability & Health Care

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Housekeeping

- All attendees are in listen-only mode
- Webinar is being recorded
- Slides were sent out in advance to those registered
 - Slides will also be available with the recording and sent in follow-up email
- Participants can enable closed captioning

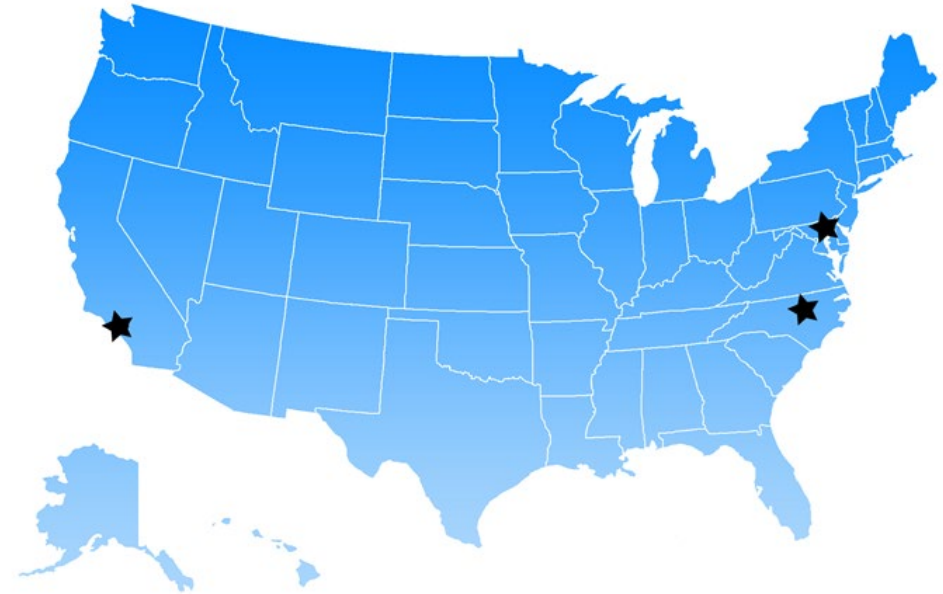
NHeLP's Mission

The National Health Law Program (NHeLP) protects and advances the health rights of low-income and underserved individuals to access high quality health care. NHeLP advocates, educates, and litigates at the federal and state levels.

We stand up for the rights of the millions of people who struggle to access affordable, quality health care.

About the National Health Law Program

- National non-profit organization committed to improving health care access, equity, and quality for underserved individuals and families
- State & Local Partners:
 - Disability rights advocates – 50 states + DC
 - Poverty & legal aid advocates – 50 states + DC
- National Partners
- Offices: CA, DC, NC
- www.healthlaw.org
- Follow us on Bluesky [@nhelp.bsky.social](https://bsky.app/profile/nhelp.bsky.social)
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NHeLP's Equity Stance

Health equity is achieved when a person's characteristics and circumstances — including race and ethnicity, sex, gender identity, sexual orientation, age, income, class, disability, health, immigration status, nationality, religious beliefs, language proficiency, or geographic location — do not predict their health outcomes.

<https://healthlaw.org/equity-stance/>

Overview

- Basic Legal Protections
- Medicaid Eligibility
- Home and Community Based Services
- NHeLP's Disability Litigation
- Administrative and Regulatory Policy
- What's up next for disability?
- NHeLP's Disability Partners

Basic Legal Protections

Basic Legal Protections

- Section 504
- ADA
- Olmstead v. L.C.
- 1557 of the Affordable Care Act
- Medicaid

Section 504 of the Rehabilitation Act of 1973

- One of the first major federal disability rights law:

“No otherwise qualified individual with a disability in the United States, shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.”

- Applies to programs and activities that receive Federal funding:
 - Schools
 - Hospitals
 - Medicaid and Medicare
 - Libraries
 - Courtrooms
 - Federal government itself

Americans with Disabilities Act

- Passed in 1990, updated in 2008
- The ADA prohibits discrimination on the basis of disability in:
 - (Title I) Employment,
 - (Title 2) State and local government activities, public transportation
 - (Title 3) Public accommodations, commercial facilities, and
 - (Title 4) Telecommunications

Right to Community Living: Olmstead v. L.C.

- Segregation is a form of discrimination
- Unjustified institutional isolation
 1. Perpetuates unwarranted assumptions that people are incapable or unworthy of participating in community life
 2. Severely diminishes everyday life activities, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment

Section 1557 of the Affordable Care Act

- Passed 2010, regulations last updated 2024
- Makes it unlawful for any health care provider that receives funding from the Federal government to refuse to treat an individual – or to otherwise discriminate against the individual
 - Race
 - Color
 - National origin
 - Sex
 - Age
 - Disability

Eligibility

Eligibility Categories

- Over 40 eligibility categories in Medicaid
- Categories have different income and resource standards, and some are based on disability, age, and other status.
- There are different ways to calculate income, depending on the category.
- Assets are counted for some categories but not others.

Eligibility – Pre-ACA

- Four hurdles
 - State resident;
 - Citizen or qualified immigration status;
 - Fit into category: older adult, individuals with disabilities, parents, pregnant women, or children; and
 - Extremely limited income and resources

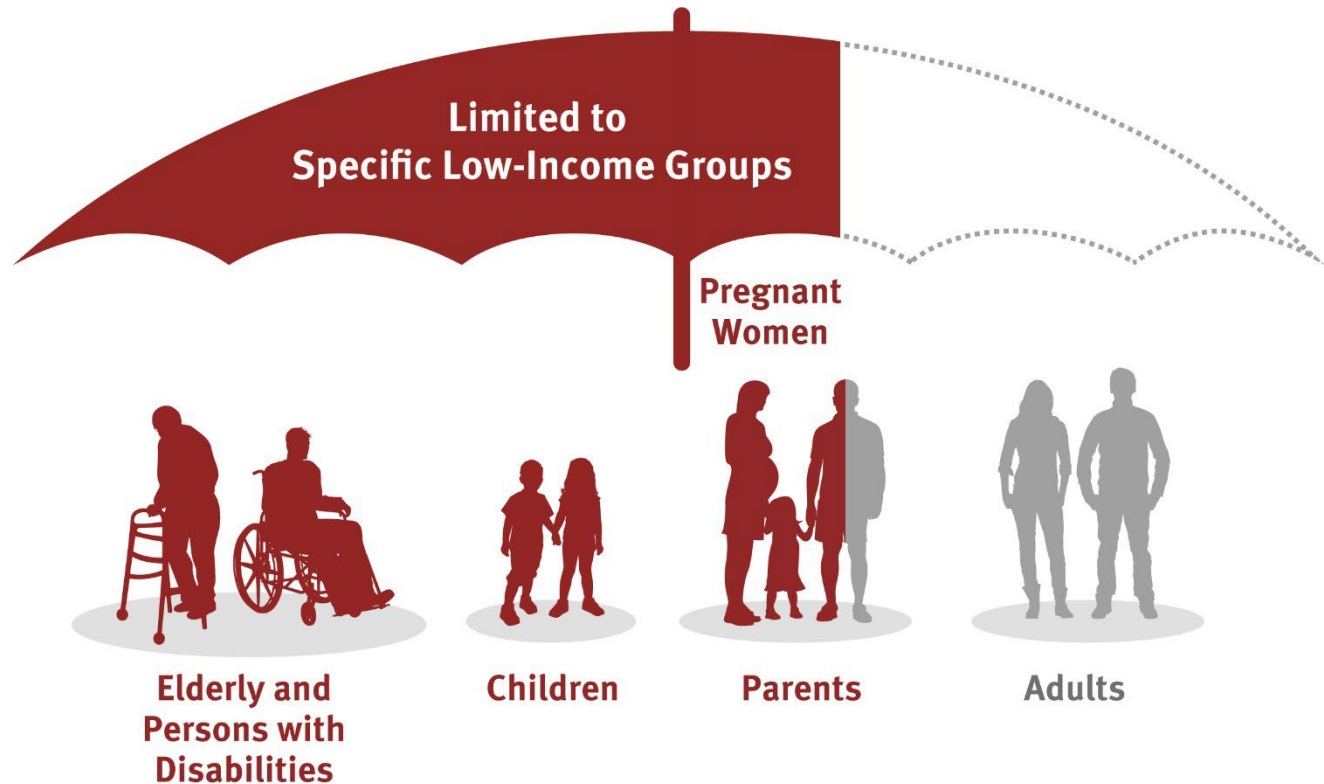
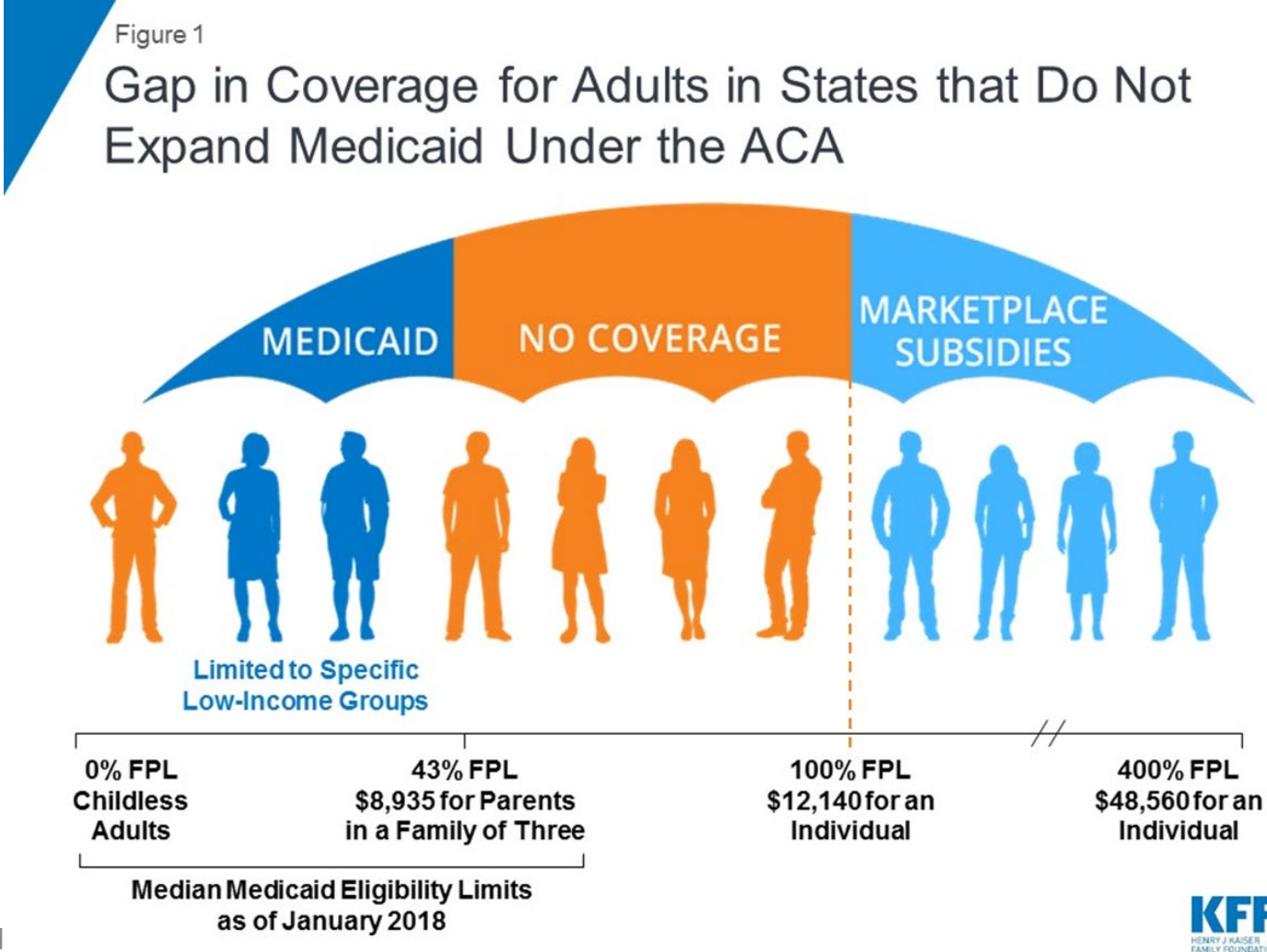


Image source: Kaiser Family Foundation

Vital Importance of Expansion



Medicaid Expansion and People with Disabilities

- Currently 40 states, plus the District of Columbia have adopted Medicaid expansion, providing important coverage for people with disabilities and chronic health conditions.
- Estimates indicate that between [1/5 and 1/3 of Medicaid expansion enrollees](#) have a disability.
- Medicaid expansion provides critical access to a variety of services including mental health and substance use disorder treatment.

Home and Community Based Services (HCBS)

Mandatory vs. Optional Medicaid Services

Mandatory Services = Services the state is required to provide under federal law

- Nursing facility services are mandatory services

Optional Services = Services a state may choose to cover under Medicaid

- HCBS services are optional services

LTSS – Medicaid's Expertise

- Medicaid is the single largest purchaser of long-term services and supports (LTSS) in the nation
- Institutional long-term care – covers nursing facilities and ICFs. Generally does not cover long term psychiatric facilities.
- LTSS includes Home and Community Based Services (HCBS)

What are Home and Community Based Services?

Assistance getting through the tasks of managing your body and your everyday life.

Activities of Daily Living (ADLs)

Eating



Getting Around



Grooming



Instrumental Activities of Daily Living (IADLs)

Housekeeping



Managing Money



Cooking

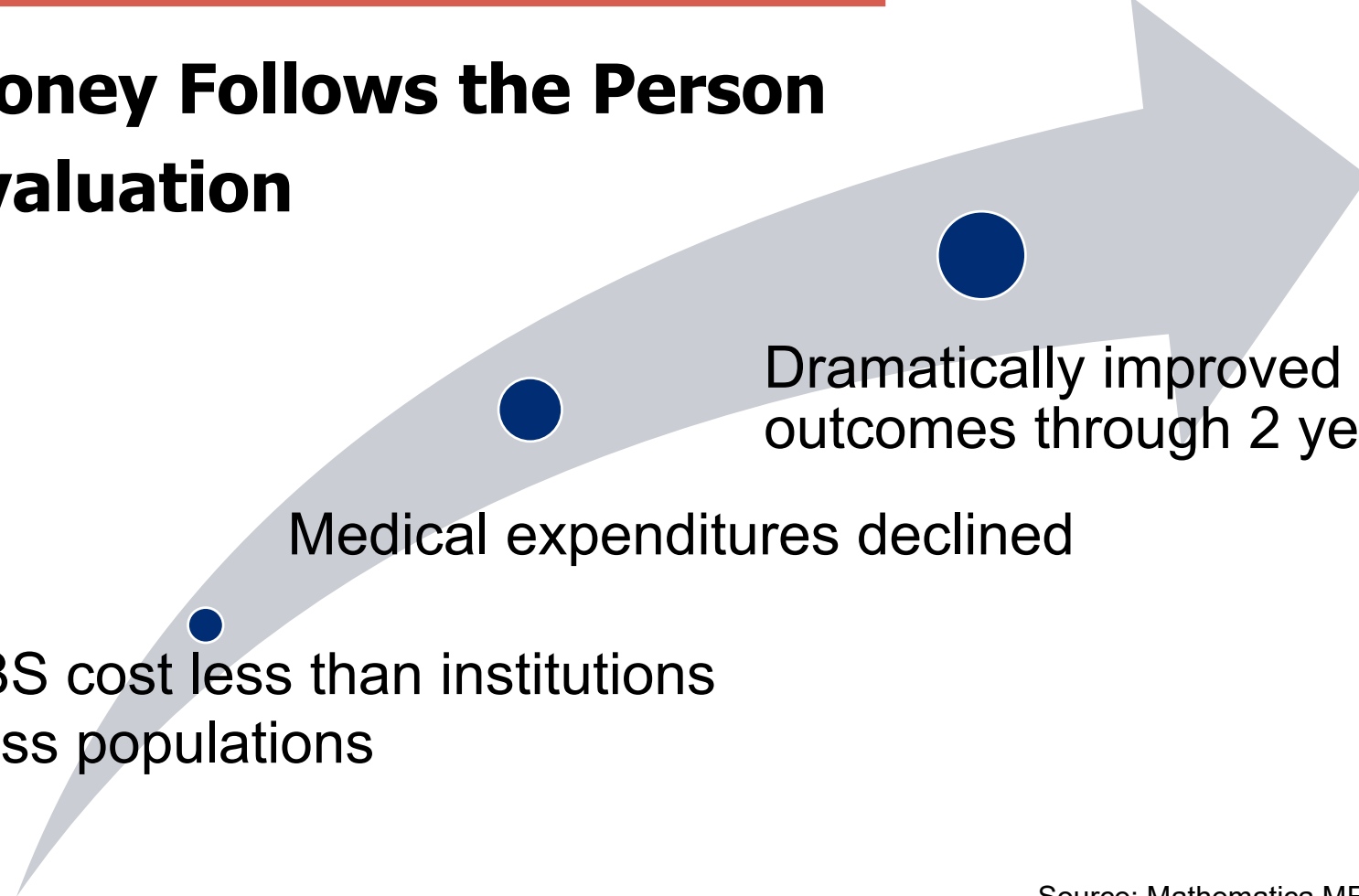


What Is the Purpose of HCBS?

- Medicaid HCBS support people with disabilities in their homes and communities, enabling them to live in integrated settings rather than in institutional settings (e.g., intermediate care facilities or nursing facilities).
- Promote autonomy, dignity, and full access to the benefits of community living
- Prevent people with disabilities from entering institutions unnecessarily and enable them to leave institutions

Cost of Institutions vs. HCBS?

Money Follows the Person Evaluation



HCBS cost less than institutions
across populations

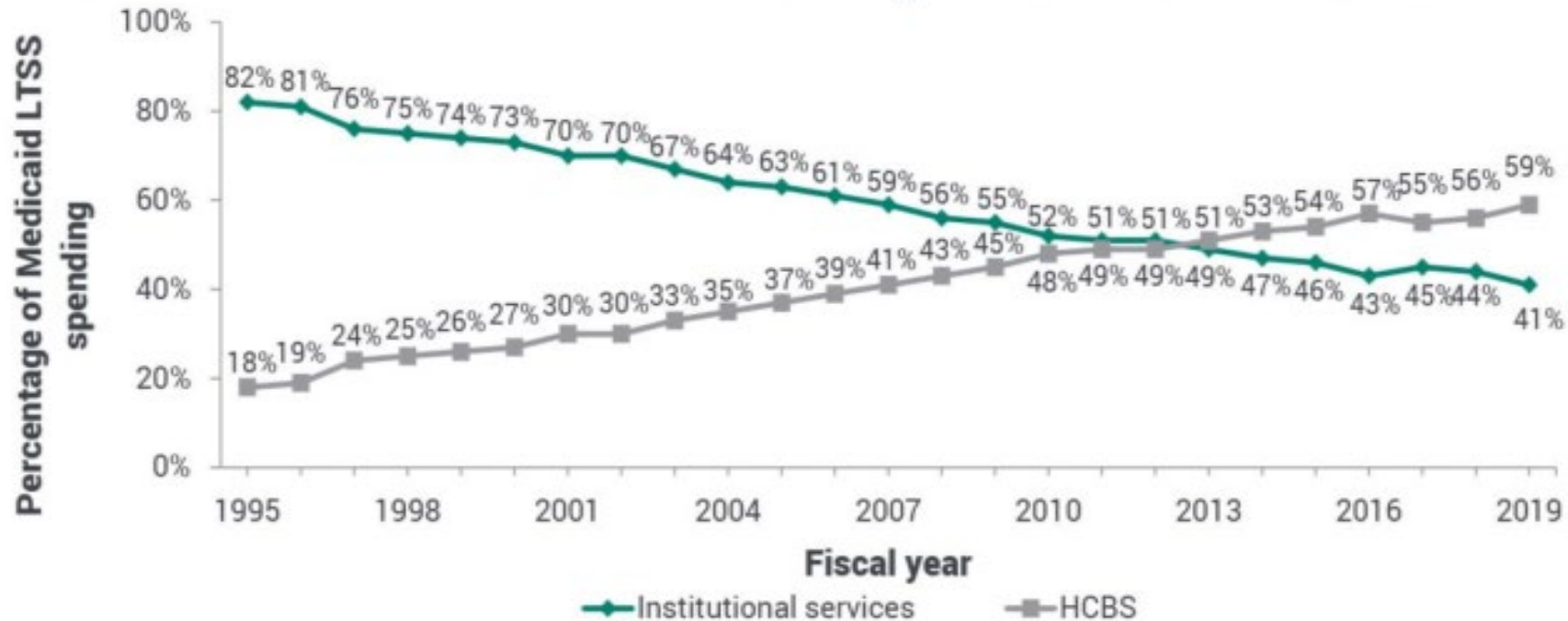
Medical expenditures declined

Dramatically improved
outcomes through 2 years

Source: Mathematica MFP Annual
Evaluation Reports, 2012 & 2014

Community Integration

Proportion of Total Medicaid LTSS Spending on Institutional LTSS and HCBS, FYs 2000–2019



Source: MACPAC,
<https://www.macpac.gov/subtopic/home-and-community-based-services/>

HCBS in Medicaid

- Access to HCBS is typically provided through 1915(c) waivers or state plan HCBS options like 1915(i) or 1915(k) Community First Choice
- Many states have lengthy waitlists due to capped enrollment in 1915(c) programs
- Most children receive HCBS through EPSDT



- Early & Periodic Screening, Diagnostic, & Treatment
 - Medical screens and other required screening at preset periodic intervals and when a problem arises
 - Medically necessary diagnostic and treatment services
- Mandatory for Medicaid-eligible children and youth up to age 21
- Outreach and reporting
- Why?
 - Children are not little adults
 - Adolescents are not big children
 - Particularly critical for lower-income children because health status tends to decrease along with income

Section 1915(c) – HCBS Waiver Program

- Targeted population
- Set of services that offer choice to institutional care
- Limits on enrollment and may have waitlists
- Periodic renewal and budget neutrality required
- Eligibility based on level of care (typically institutional)
 - May have higher income limits or different rules for counting income
 - Waiver eligibility is Medicaid enrollment
- Self-direction options
- Section 1115s may have “1915(c) like” services

Common 1915(c) Services

- Residential habilitation (e.g., group home), day habilitation
- Prevocational and supported employment services
- Occupational, speech, language, physical therapy
- Behavior management
- Respite services
- Personal care services
- Adult day health services
- Other services requested by the state as the Secretary may approve

NHeLP's Litigation on Disability Issues

Disability-Related Litigation

- Americans with Disabilities Act, Section 504, Section 1557 claims often with Medicaid Act and/or Due Process claims
- Discrimination in the administration of programs and services, like Medicaid
 - *Olmstead* enforcement, particularly protecting people from the risk of unnecessary institutionalization or segregation from the community
 - Access to services – addressing discriminatory administration of services or coverage/benefit design
 - Eligibility issues – systems and processes that screen out people with disabilities
- Amicus briefs
- Administrative practice
- Technical assistance on other cases

Case Examples

- Children's access to intensive home and community-based behavioral health services
 - *e.g.*, CO, IA, GA, LA, MI, NY
- Children's in-home nursing services
 - Settlement implementation in several states (IL, LA, MO)
- Notice and due process regarding eligibility
 - *e.g.*, TN, FL, NC
 - Note: in TN case, *AMC v. Smith*, the court found violations of the ADA because of eligibility system issues
- History of challenging cuts to services that created risk of unnecessary institutionalization; assessment tools for HCBS; screening and services for children; equal access to care

Administrative & Regulatory Policy

Hierarchy of Laws

Statute →

- Passed by Congress & Signed by President
- Can't be changed without enacting a new law

Regulations →

- Developed by Agencies
- Requires public comment process
- Can't be changed without a new public comment process

Guidance

- Developed by agencies
- Usually no public comment process
- Can be changed by the agency
- Includes Executive Orders, FAQs etc.

Administrative and Regulatory Concerns

- Administrative repeal or weakening of key rules
 - Access Rule (HCBS sections take effect over 10 years)
 - HCBS Settings rule (fully implemented 2023)
 - HHS Section 504 rule (took effect 2024)
 - Section 1557 rule (took effect 2024)
- Potentially little or no federal enforcement
- Expect more success in state-level policy

Looking Ahead: What's Up Next for Disability?

What's Next?

- Cuts to Medicaid funding
- Work requirements
- Higher out-of-pocket costs
- Unintended care denials due to burdensome eligibility & enrollment processes
- Anti-immigrant funding cuts threatens HCBS & direct care workforce

NHeLP's Work: Partnerships & Coalitions

Coalitions

- [Consortium for Constituents with Disabilities](#)
 - CCD is the largest coalition of national organizations advocating for federal public policy that ensures the self-determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society
- Disability & Aging Collaborative
 - DAC is a coalition of approximately 60 national and state organizations that work together to advance long-term services and supports policy at the federal level

Resources

- [NHeLP's Disability Practice Area](#)
- [Overview of Key HCBS Provisions in the Medicaid Access Rule](#)
- [Power of 504](#)
 - Award-winning 18-minute documentary video, which captures the drama and emotions of the historic civil rights demonstration of people with disabilities in 1977, resulting in the signing of the 504 Regulations
- [Change, Not Charity: The Americans with Disabilities Act](#)
 - The emotional and dramatic story of the decades-long push for equality and accessibility that culminated in the passage of the Americans with Disabilities Act (ADA) in 1990

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