MEDICAID HOME AND COMMUNITY-BASED SERVICES (HCBS)

NDSC POSITION

Medicaid Home and Community-Based Services (HCBS), often referred to as waiver services, provide essential supports that enable people with Down syndrome and other intellectual and developmental disabilities to live, work, and participate in their communities rather than being forced into institutional settings. HCBS include daily living assistance, employment supports, transportation, therapies, assistive technology, and respite services that promote independence, dignity, and community inclusion.

Despite their importance, many HCBS programs remain optional under federal Medicaid law, allowing states to limit enrollment and maintain waiting lists. Inadequate funding, workforce shortages, complex eligibility requirements, and administrative barriers threaten access to essential services, placing significant burdens on individuals and families and increasing the risk of unnecessary institutionalization.

NDSC supports protecting, strengthening, and expanding Medicaid-funded HCBS, including making these services a mandatory Medicaid benefit, to ensure people with Down syndrome and other disabilities have timely, equitable access to individualized supports and meaningful choices about how and where they live.

POLICY PRIORITIES

NDSC supports policies that protect and strengthen Medicaid-funded HCBS and opposes cuts, funding restrictions, or structural changes that reduce access to essential community-based services or increase the risk of unnecessary institutionalization.

NDSC's highest HCBS priorities are to:

Make HCBS a mandatory Medicaid benefit rather than an optional waiver service, ensuring eligible individuals have timely access to necessary supports without waiting

lists, arbitrary caps, or geographic disparities;
- Protect and strengthen Medicaid funding for HCBS and oppose cuts, block grants, per capita caps, restrictions on federal Medicaid financing, or other changes that reduce states' ability to provide essential community-based services;
- Reduce and eliminate HCBS waiting lists and expand access to services so individuals and families are not forced to wait years for critical supports and are able to move to different states without going to the bottom of the list;
- Strengthen the Direct Support Professional (DSP) workforce through improved wages, training, benefits, and career pathways to ensure the availability, quality, and continuity of community-based services; and
- Uphold and enforce the civil rights protections of the Americans with Disabilities Act (ADA) and the Supreme Court's Olmstead decision, preventing unnecessary institutionalization and ensuring services are provided in the most integrated setting appropriate.

Additional Priorities

Individual Choice and Community Living

- Expand self-directed and person-centered services, ensuring individuals have meaningful choice and control over their supports, providers, staff, schedules, and living arrangements, including access to supported decision-making;
- Expand access to affordable, accessible, integrated housing and protect individuals' ability to choose where and with whom they live, without unnecessarily tying housing to a particular service provider;
- Preserve and expand essential community supports, including employment services, transportation, therapies, assistive technology, respite, and other services that promote independence and community participation; and
- Support flexible HCBS policies that allow qualified family members and others chosen by the person receiving services to provide paid supports, with appropriate safeguards, while preserving access to professional services.

Eligibility, Access, and Continuity of Services

- Protect continuity of HCBS during Medicaid eligibility reviews, renewals, appeals, and administrative disruptions, including safeguards to prevent service interruptions and maintain provider payments;
- Oppose Medicaid work requirements and other administrative barriers that place people with disabilities at risk of losing eligibility for essential healthcare and community-based services;
- Simplify Medicaid eligibility, enrollment, and renewal processes to prevent wrongful terminations and coverage disruptions;

- Modernize Medicaid income and asset eligibility rules, expand Medicaid Buy-In programs, and eliminate financial disincentives that prevent people with disabilities from working, saving, or marrying without jeopardizing HCBS; and
- Expand access to emergency and crisis stabilization services to prevent unnecessary hospitalization, institutionalization, or loss of community living arrangements.

Provider Stability, Quality, and Accountability

- Ensure adequate and sustainable reimbursement for community service providers, including safeguards to maintain services and provider payments during Medicaid eligibility disruptions and administrative delays;
- Strengthen federal and state oversight, transparency, and accountability to ensure service quality, individual rights, health and safety, and meaningful participation by people with disabilities in HCBS policy development and oversight; and
- Promote equitable access to HCBS across states and communities, including rural and underserved areas, and improve coordination among Medicaid, developmental disability agencies, and other service systems.

BACKGROUND AND LEGAL FOUNDATION

Medicaid HCBS have evolved over decades to provide alternatives to institutional care and support the right of people with disabilities to live in their communities. The Social Security Act established Medicaid in 1965, and subsequent amendments authorized states to provide HCBS through waiver programs and other Medicaid authorities. However, many HCBS programs remain optional, allowing states to limit access through enrollment caps, waiting lists, and other restrictions.

The Americans with Disabilities Act (ADA) and the Supreme Court's landmark *Olmstead v. L.C.* decision established that unjustified institutionalization of people with disabilities constitutes discrimination and that states must provide services in the most integrated setting appropriate. The Medicaid HCBS Settings Rule further established requirements for community integration, individual choice, and person-centered services.

For people with Down syndrome, HCBS provide essential supports that make community living possible. Without adequate services, individuals may face unnecessary institutionalization, families may experience significant financial and caregiving burdens, and opportunities for independence and inclusion may be lost. Inadequate funding, workforce shortages, restrictive eligibility rules, and administrative barriers further threaten access to these supports.

Protecting and expanding Medicaid-funded HCBS is essential to ensuring that people with Down syndrome can exercise their civil rights, pursue employment, maintain meaningful relationships, and live with dignity, independence, and full inclusion in their communities.

Key Authorities

- Social Security Amendments of 1965, Pub. L. No. 89-97, 79 Stat. 286 (1965) (establishing Medicaid)
- Omnibus Budget Reconciliation Act of 1981, Pub. L. No. 97-35, 95 Stat. 357 (1981) (establishing § 1915(c) HCBS waivers)
- Social Security Act §§ 1915(c), 1915(i), 1915(j), and 1915(k), 42 U.S.C. § 1396n (Medicaid HCBS and self-direction authorities)
- Social Security Act § 1902(a)(3) and (8), 42 U.S.C. § 1396a(a)(3), (8) (fair hearings and reasonable promptness)
- Rehabilitation Act of 1973, § 504, 29 U.S.C. § 794
- Americans with Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 327 (1990)
- Olmstead v. L.C., 527 U.S. 581 (1999)
- Deficit Reduction Act of 2005, Pub. L. No. 109-171, 120 Stat. 4 (2006) (Money Follows the Person)
- Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010) (expanding HCBS authorities)
- Medicaid HCBS Settings Rule, 79 Fed. Reg. 2948 (2014)
- Medicaid Access Rule, 89 Fed. Reg. 40542 (2024), as subsequently amended