The National Down Syndrome Society, the leading human rights organization for all individuals with Down syndrome, supports constructive federal reforms to the state-based Medicaid program that promote home and community-based services, improve the coordination of care and services due resulting from medical complexities, and facilitate economic independence for people with Down syndrome.

Medicaid is vitally important for people with Down syndrome who generally do not have access to employer-based or other private coverage. Moreover, people with Down syndrome can have significant medical needs, and often require assistance with activities of daily living throughout their lives. Through Medicaid Long-Term Services and Supports (LTSS), people with Down syndrome can also receive employment supports that enable them to both attain and maintain gainful employment. Home and community-based services (HCBS) also provide opportunities for Medicaid beneficiaries to receive services in their own home or community rather than institutions or isolated settings.

As the 115th Congress and the Trump Administration consider changes and reforms to the Affordable Care Act (ACA) and Medicaid, NDSS urges policymakers to fully address the health needs, access to care and vast scope of services (i.e., housing, job supports, and employment) that programs like Medicaid offer to all individuals with Down syndrome. Medicaid is a program that reaches far beyond the scope of healthcare for individuals with Down syndrome and encourages people with Down syndrome to live and work in their communities, develop assets that reduce dependence on public benefits, and avoid costly and segregated nursing homes or institutions.

NDSS looks forward to working in a bipartisan fashion to ensure that the following principle are incorporated into any Medicaid reform legislation considered by Congress:

**Block Grants & Per Capita Caps** – NDSS is concerned about proposals to block grant Medicaid funds or allocate funds based on current spending per enrollee or category of enrollee, with payment caps set for different subpopulations, either nationally or per state. Establishing high-risk pools, defining subpopulations and/or setting fixed amounts could be complex, arbitrary, and detrimental to people with Down syndrome, many of whom would not fit neatly into one category of complexity or subpopulation. According to the National Institutes of Health, at least one-half of all people with Down syndrome also have co-occurring conditions that contribute to their medical complexity. For example, approximate half of all children with Down syndrome are born with congenital heart disease. A person with Down syndrome may also be defined as a person with a disability, a person with cancer, and a person with Autism, and a person with Alzheimer’s disease. Proposals that provide for block grants and per capita payment caps, including those that fund high-risk pools, must account for the many combinations of complicated health care needs that people with Down syndrome will face throughout their lifespan.

**Improve Access to Coordinated Care** – All individuals with Down syndrome have health and long-term support needs irrespective of where they live, their families’ level of income and their day-to-day challenges. These needs will vary among individuals and for each individual throughout the lifespan. Medicaid reforms should address the complex medical needs of people with Down syndrome in their entirety. Incorporating the ACE Kids Act (S. 298 and H.R. 546 in the 114th Congress) is one way to improve the process by which individuals with Down
syndrome who participate in the Medicaid program, and who also have other complex medical conditions, can obtain quality care and coordinated treatments.

**Provide Essential Supports and Services** – Individuals with Down syndrome who currently have access to healthcare and/or long-term supports and services from Medicaid, CHIP and/or health insurance (subsidized or available from employers) should not lose those benefits as a result of health care reform. In fact, such reforms should include sufficient resources to address the much needed supports and services of thousands of people with Down syndrome on very long waiting lists across the country.

**Address Lifespan Needs** – Due to advances in medical technology, individuals with Down syndrome are living longer than ever before. Today, as many as 80 percent of adults with Down syndrome reach the age of 60, and many live even longer. This necessitates access to affordable health care and long-term services and supports throughout an increased lifespan. Efforts to reform the Medicaid program should seek to address the gaps and barriers to health care that prevent individuals with Down syndrome from experience a high quality of life as they transition from childhood to working adult to senior citizen. This includes access to wellness and prevention services, health and health disparities research, patient-centered care models, and increased professional training for health care providers.

**Incentivize Productivity and Work** – The current eligibility framework for Medicaid penalizes work and employment for individuals with Down syndrome. Future reforms should incorporate changes that improve opportunities for people with Down syndrome and other disabilities to obtain integrated employment and reduce their relegation to subminimum wages and segregated environments. Medicaid reforms should include incentives for states to meeting certain benchmarks for expanding employment opportunities for people with Down syndrome and other disabilities within the state, and offer cost-effective supports and services that promote self-determination, independence, productivity, and integration and inclusion.

**Strengthen Wrap-Around Services** – Medicaid and CHIP provide access to healthcare and long-term services and supports that wrap-around limited healthcare benefits provided by employer-sponsored coverage. Enhancing the ability of these programs to complement existing coverage should be a priority of Medicaid reform, especially as it relates to ensuring that people with the most significant needs are able to access the lifelong interventions and supports they need.

**Portability** – Down syndrome is the most commonly occurring chromosomal condition, affecting approximately one in 700 babies born in the U.S. each year. It affects all races, ethnicities, genders and knows no geographic boundaries. Individuals must be able to access needed supports where they live but also be free to travel across state lines to seek care from specialists and specialty Down syndrome clinics that are scattered throughout the country.