March 8, 2017

To Members of the U.S. Senate and House of Representatives:

On behalf of the National Down Syndrome Society, the leading human rights organization for all individuals with Down syndrome, I am writing to express the views of our organization on Budget Reconciliation legislative recommendations relating to the repeal and replacement of the Affordable Care Act (ACA). As you know, vital provisions contained in the ACA and Medicaid continue to be critical to people with Down syndrome. NDSS supports several provisions in ACA - such as an expansion of health coverage reforms to the insurance market, nondiscrimination provisions, and long-term services and supports – that are important to the ability of people with Down syndrome to live healthy, independent and fulfilling lives.

As this legislation is considered in the coming weeks, we urge legislators to work in a bipartisan manner to: 1) continue to address and strengthen the ACA priorities outlined below; 2) enact additional reforms to promote independence and self-determination for individuals with Down syndrome and other disabilities; and 3) protect and preserve Medicaid’s current funding structure by removing from the legislation provisions to convert Medicaid to a block grant system and establish a per capita spending cap for the disability community.

Existing ACA Policies Benefiting All Individuals with Down Syndrome

The following are policies in existing law that are critical to people with Down syndrome, and NDSS urges the Administration and Congress to sustain or enhance them:

Maintain dependent coverage: People with Down syndrome follow a longer transition period going from youth to adulthood. Their vocational, domestic, and social and personal skills take longer to develop, and the responsibilities of identifying, locating and coordinating appropriate health care resources and services for the complex medical conditions facing young adults with Down syndrome fall primarily on their families. Allowing individuals with Down syndrome to stay on their parents’ private health insurance plan until age 26 is essential to their ability to achieve independence and community integration.

Guarantee availability and renewal: All individuals with Down syndrome have pre-existing and co-occurring medical conditions that could undermine access to universal and continuous health insurance coverage. These includes cognitive impairment, congenital heart defects, leukemia, obstructive sleep apnea, seizure disorders, neurobehavioral problems, pulmonary hypertension, thyroid diseases, celiac disease, gastrointestinal defects, Type 1 diabetes, immune system dysfunction, metabolic dysfunction and mental health disorders, to name a few. As a result of the ACA’s prohibition on exclusions for pre-existing conditions, combined with guaranteed renewability
of coverage, individuals with Down syndrome now have access to affordable private health insurance coverage.

Ensure affordable access to habilitative and preventative services: Since the implementation of the ACA, developmental screening is now a covered preventive service for children. In addition, non-grandfathered health plans in the individual and small-group markets are required to cover rehabilitative and habilitative services and devices. This is particularly important for individuals with Down syndrome, who typically face delays in basic physical, cognitive, language, social and self-help skills. Their having access to early intervention and habilitative services is critical for achieving optimal health outcomes, improving skills and functioning for daily living, and becoming active and productive participants in their communities.

Maintain the Community First Choice State Plan Option: This program expands Medicaid opportunities for the provision of home and community-based long-term services and supports (LTSS), and facilitates community integration. Many people with Down syndrome are not in the labor force and lack access to employer sponsored health insurance. Many others are employed but have grandfathered private insurance plans that do not cover many disability related therapies and services. Without access to LTSS, individuals with Down syndrome will be denied opportunities to work in meaningful and competitive employment settings.

Prohibit annual and lifetime caps in private insurance policies: The ACA prohibits health plan and insurance policies from imposing annual and lifetime dollar limits on total benefits the amount of coverage an individual may receive. According to the National Institutes of Health, at least one-half of all children with Down syndrome also have co-occurring conditions that contribute to their medical complexity. Limits on benefits would prevent people with Down syndrome from obtaining needed, but costly, surgeries, therapies, medical equipment and prescription drugs.

In addition to continuing certain provisions of current law, NDSS urges the Administration and Congress to support additional reforms that can improve the health and wellbeing of individuals with Down syndrome in a cost-effective way. Such reforms include:

Enact the Advancing Care for Exceptional (ACE) Kids Act: Because their complex medical conditions can be costly, many children with Down syndrome depend on state-based Medicaid programs. They also require specialized care in centers of excellence, often times outside of their state. Unfortunately, current Medicaid rules can limit access to coordinated care and restrict options to receive medical treatment by out-of-state specialists. The ACE Kids Act is legislation to create a mechanism for states to participate in a national framework for children with medical complexities to receive cost-effective and coordinated health care and support. This framework could significantly reduce the necessity for more extensive medical interventions later in life, thus improving the long-term financial viability of the Medicaid program.

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.

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 experiencing 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.

How Block Granting Medicaid Funding and Per Capita Payment Caps Could Impact 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. In addition, Medicaid is a program that reaches far beyond the scope of healthcare for individuals with Down syndrome. It 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. For example, 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.

Specifically, 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. According to the National Institutes of Health (NIH), 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. Therefore, unless calibrated correctly, block grants and per capita spending caps – even those that establish high-risk pools, define subpopulations and/or set 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.

In closing, NDSS supports constructive federal health care reforms 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. As Congress considers reforms to the ACA and Medicaid, we urge you 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.
We, at NDSS, continue to appreciate the opportunity to work with you to fashion health care reforms that improve health outcomes and increase access to quality care, while also promoting independence and self-determination for individuals with Down syndrome.

Thank you for all you do for individuals with Down syndrome and their families!

Sincerely,

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