

- » Ensure that community-based first responders (e.g., police, emergency medical services, emergency room personnel) are equipped with knowledge about working with people who have I/DD and who are experiencing a behavioral and/or mental health crisis;
- » Ensure that the provisions of the Mental Health Parity and Addiction Equity Act along with the mental/behavioral health and substance use services provisions in the ACA are fully funded and implemented; and
- » Ensure sufficient reimbursement rates for mental/behavioral health service providers in order to promote improved access to needed services.

Other

- » Reauthorize and fully fund the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act; and ensure more research on individuals across the lifespan and in diverse populations;
- » Reduce harmful chemical exposures that are associated with I/DD;
- » Ensure access to medical cannabis for people who can benefit from it;
- » Recognize developmental and other disabilities as medically underserved populations;
- » Ensure that measures intended to curb drug abuse do not place an undue burden on access to properly prescribed medications, including pain management medications;
- » Strengthen consumer protections to protect people with I/DD from unsafe or untested treatments; and
- » Ensure that medical research is patient-centered in design and implementation.

MEDICAID

Medicaid is an essential program for most people with significant disabilities. Medicaid is overwhelmingly the largest funding source

of long term individual and family supports in the federal/state I/DD service system, and the primary source of health care payment for many of our constituents. For the increasing number of individuals with disabilities living with aging parents, Medicaid will continue to be essential to meet their future need for long term supports and services.

Medicaid is also a powerful driver of economic activity at the state and local levels. When people with disabilities receive needed services, key family members are able to maintain their own employment. When Medicaid-funded service provider agencies are able to retain staff positions, unemployment is reduced and money is put into the hands of individuals who will spend it. In addition, Medicaid reduces health care costs by allowing people with disabilities to utilize home and community-based supports and services rather than costly and unnecessary institutionalization.

Many states and territories continue to have inadequate reimbursement rates and reduced services with devastating impact on people with disabilities, their families, and their communities. Today, many of our constituents cannot get necessary health care and long term services. Further shifting responsibility for Medicaid to the states and allowing states to reduce eligibility and benefits would place many of our constituents, and our nation's health, therapeutic, and long term support systems for vulnerable populations, at enormous risk. Decreased Medicaid budgets also mean that hundreds of thousands of people with I/DD will remain on waiting lists across the country.

Numerous improvements were made to the Medicaid acute and long term supports and services programs through enactment of the Affordable Care Act (ACA). These program improvements must be properly implemented at the federal and state levels in order to work most effectively for people with disabilities. States must be provided with clear guidance on how to effectively use the flexibility and options created by the ACA.

During the 116th Congress, our public policy goals are to:

Overall Structure

- » Maintain the individual entitlement to a full range of Medicaid health and long term supports and services (LTSS) for all eligible children and adults with disabilities;

- » Oppose Medicaid deconstruction or any moves to provide states with flexibility that eliminates basic protections for eligible individuals with developmental disabilities or the imposition of entitlement caps, Medicaid block grants, per capita caps, allocations, allotments, limiting provider taxes, and other proposals that shift costs to states or other mechanisms that cause reductions in eligibility, services, or protections for our constituents;
- » Oppose requirements that Medicaid beneficiaries be employed in order to receive benefits;
- » Oppose policies that would time limit Medicaid benefits;
- » Reject efforts to repeal, weaken, or block implementation of relevant provisions of the ACA;
- » Require the Centers for Medicare and Medicaid Services (CMS) provide thorough, timely, and consistent review of all state plan amendments and waivers to ensure compliance with the ADA and Olmstead; and
- » Require CMS and the states to provide full and timely public access to state Medicaid plans and waivers, including current and proposed amendments and related public comment, in formats accessible to stakeholders.

Eligibility

- » Incentivize state implementation and ensure protection of Medicaid expansion as authorized by the ACA;
- » Incentivize state implementation of the option in state Medicaid plans for families of children with disabilities to buy into Medicaid if private health insurance is not available or does not meet their needs;
- » Incentivize full implementation by states of options to establish Medicaid buy-in programs for people with disabilities who work;
- » Ensure that Medicaid eligibility rules and processes do not place undue burdens on applicants and beneficiaries who do not have access to birth or citizenship documentation;

- » Protect and improve the ability of families and individuals to establish trusts to benefit Medicaid eligible beneficiaries with I/DD and ensure the integrity of pooled trusts which serve such families and individuals; and
- » Increase the spend-down limit under Medicaid.

Benefits

- » Prohibit issuance or implementation of any regulations that limit or eliminate services;
- » Improve and expand access to the Medicaid buy-in program;
- » Ensure that Medicaid-eligible children with disabilities continue to obtain health-related services during the school day and receive any necessary accessible, affordable, accountable, and flexible transportation to those services;
- » Ensure protections for people with disabilities who are dually eligible for Medicaid and Medicare to ensure that they have timely and affordable access to all medically necessary services, supports, and medications under Medicaid, Medicare, and Medicare prescription drug plans;
- » Protect the entitlement to the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program and support sanctions against states that fail to properly implement it;
- » Expand access to dental and vision services;
- » Promote policies that ensure adequate networks of providers and access to medical and other specialists as needed;
- » Require the CMS to issue guidance to states that will result in expanded coverage of appropriate assistive technology and technology-enabled supports for Medicaid beneficiaries, including eliminating barriers to multi-use and commercial off-the-shelf technology that could support independent living in the community;
- » Ensure Medicaid reimbursement for a 30-day emergency supply of medication in anticipation of potential disasters, epidemics, or other emergencies;

- » Support the continuation and expansion of habilitation services under the Medicaid rehabilitation option and other appropriate options and ensure that our constituents have supports, services, and training available to teach them to achieve self-determination and increase independence, productivity, and full citizenship through greater mental, physical, and social development; and
- » Ensure the availability of accessible, affordable, accountable, and flexible transportation to facilitate full community participation.

Home and Community-Based Services (HCBS)

- » Ensure full implementation and enforcement of the HCBS settings rule for both residential and non-residential services, including adequate funding, technical assistance, appropriate individualized transportation options to ensure community integration, and other necessary supports to states;
- » Change Medicaid law to mandate HCBS and require a waiver to provide services in institutions;
- » Ensure that states have plans to provide services to individuals with I/DD who live with aging caregivers or who are in other crisis situations, and allow reimbursement for future planning services;
- » Change Medicaid law so that individuals and families can choose to exercise control over resources to better meet their individual needs;
- » Require CMS to establish policy to include HCBS under the equal access rule, which requires rates to be set to ensure equal access to services;
- » Ensure the full implementation of the Community First Choice (CFC) Option which allows states to provide comprehensive community-based services with an incentive of a six-percent increase in the federal matching rate for such services;
- » Ensure full implementation of the amended section 1915(i) Medicaid state plan option for home and community-based

services that allows states to serve people who do not yet need an institutional level of care;

- » Ensure full implementation of all other long term services provisions and expansions included in the ACA to meet the needs of people with disabilities, including the state rebalancing provisions, expansion of the Money Follows the Person demonstration program, expansion of the Aging and Disability Resource Centers, and the spousal impoverishment provisions;
- » Revise Medicaid law to require states to serve all federally Medicaid eligible people with developmental disabilities and not allow states to serve only a subset of the population;
- » Enact a requirement that states implement the CFC Option;
- » Fully implement the Medicaid HCBS waiver program and state Medicaid plan Section 1915(i) option to promote competitive integrated employment;
- » Ensure that amount, duration, and scope of HCBS are provided on the basis of individual need identified through a person-centered planning process; and
- » Expand funding for training of all providers about the needs of children and adults with disabilities, including best practices to promote health and wellness, cultural competency, practices to prevent secondary conditions, and systems to help transition youth with disabilities to adult care providers.

Removal of Institutional Bias

- » Address unmet needs in the community by removing the institutional bias for Medicaid long term supports and services by amending the Medicaid formula for cost-sharing with the states to provide a greater fiscal incentive for supporting individuals in the community rather than in institutions; and
- » Decouple eligibility for HCBS waivers from eligibility for institutional services.

Portability

- » Improve Medicaid so that benefits are portable from state to state, so that beneficiaries and families are not disadvantaged or deprived by moving from one state to another;
- » Support clarification that states have current authority to facilitate portability; and
- » Support a project by CMS to demonstrate interstate portability of benefits with state coordination and cooperation.

Reimbursement Rates

- » Increase federal funding for HCBS through incentive payments to states of increased federal matching funds for community-based services;
- » Ensure that states set and update reimbursement rates annually so that they reflect the actual cost of providing Medicaid funded supports and services, particularly state and federal mandates, adequate wages and fully funded benefits for direct support professionals, and reimbursement rates and fees for health care practitioners; and
- » Require strong federal oversight of the adequacy of rate setting methodologies to ensure rates are sufficient to comply with federal and state mandates.

Managed Care

- » Ensure that individuals receiving services in a managed care system have the right to a person-centered plan which is generated by an assessment and a care coordination model which are relevant to the needs of people with I/DD;
- » Ensure that individuals have the right to have their person-centered plan developed in conjunction with an entity of the individual's choosing independent of the provider and the managed care organization;

- » Recognize the necessity of Health Information Technology (HIT) or Electronic Health Records (EHR) for effective care coordination of acute and long term supports and services for people with disabilities, and provide adequate federal funding assistance;
- » Recognize the paucity of experience and claims data for managed care for LTSS and reject proposals to mandate the states to move people with disabilities who are dually eligible for Medicaid and Medicare into managed care programs until sufficient, reliable claims and outcome data from demonstration projects are collected and analyzed;
- » Maintain the prohibition against the mandatory placement of children with disabilities into Medicaid managed care without an approved waiver;
- » Require CMS to provide strong federal oversight in states where acute, behavioral health care and/or LTSS are provided through Medicaid managed care or other integrated care programs and expand existing managed care consumer protections;
- » Require transparency and meaningful opportunities for stakeholder engagement during all phases of the development and adoption of financing and service delivery changes, including concept development, contract specifications, evaluation, oversight, and CMS review of waiver applications/state plan amendments; and
- » Require CMS to require states to:
 - Structure assessment, care coordination, and rate setting methodology to include financial incentives to achieve person-centered outcomes consistent with the principles of Olmstead and the ADA;
 - Build rate setting methodology by collecting at least 2–3 years of Medicaid (and, as appropriate, Medicare) claims data, including acute, behavioral health, and LTSS claims, and workforce data as available and appropriate. Acute and behavioral health claims data should not be used to determine costs of LTSS as those supports are not medically based; articulate explicit performance

outcome measures and metrics in purchasing specifications and contract language with providers under fee for service or other entities the state uses such as accountable care organizations (ACOs) or managed care entities (MCEs); and

- Commission an independent evaluation of their managed care programs and other integrated care models and include the findings and conclusions from this evaluation in a state's renewal request.

SOCIAL SECURITY/INCOME MAINTENANCE

Social Security is not only a retirement program. It is an insurance program to protect against poverty in retirement or as a result of disability or death of a family wage earner. The Social Security Act provides Old Age, Survivors, and Disability Insurance under Title II of the Act, Supplemental Security Income (SSI) under Title XVI of the Act, and related health insurance under Medicare (Title XVIII) and Medicaid (Title XIX). Approximately one-third of all Social Security checks go to non-retirees, including approximately ten million people with disabilities. These beneficiaries include workers with disabilities and people with disabilities who are dependents and survivors of disabled workers, retirees, and deceased workers. Many depend solely on their Social Security or SSI benefits and related health coverage for their basic survival. Discussions about Social Security reform, however, usually focus on retirement benefits and seldom address potential effects on people with disabilities in the retirement, disability, and survivors programs.

We support efforts to ensure the solvency of the Social Security Trust Funds over a 75-year time frame while preserving the program's basic structure and strengthening its insurance functions. We do not support efforts to create private accounts out of the Social Security Trust Funds. The impact of the resulting market risk, benefit cuts, or additional trillions of dollars in deficits would be devastating for people with disabilities.

In recent years, inadequate funding of SSA's operating budget has eroded the agency's services across the board. People with disabilities have experienced long delays and decreased service