



January 8, 2010

President Barack Obama
The White House
1600 Pennsylvania Avenue NW
Washington, DC 20500

Honorable Nancy Pelosi
Speaker of the House
U.S. House of Representatives
235 Cannon House Office Building
Washington, DC 20515-0508

Honorable Harry Reid,
Senate Majority Leader
U.S. Senate
522 Hart Senate Office Building
Washington, DC 20515-2005

Dear President Obama, Speaker Pelosi and Majority Leader Reid:

We write as members of the Justice for All Action Network (JFAAN), a coalition of organizations of, by, and for people with disabilities to applaud the progress made in health care reform to cover more Americans, eliminate pre-existing condition exclusions, make health care more affordable, and improve the health of Americans. We believe health care reform will benefit the disability community. We urge you to consider the following policy suggestions for inclusion in the final bill and/or report language so that the final legislation addresses the acute and long-term health needs of the more than 50 million Americans with disabilities.

In general, we encourage you to take steps to ensure that the enactment of health reform legislation does not undermine existing state policies that currently provide insurance coverage for home and community based services, durable medical equipment that facilitates independent living, and hearing-related services and equipment. Particularly in a difficult fiscal environment, States need every incentive to continue providing these services under Medicaid and other programs, and we encourage you to include maintenance of effort language for these critical services in the final legislation.

We acknowledge the importance of prevention and wellness programs for persons with disabilities. However, we urge you to make sure the final bill does not cause persons with disabilities to face discriminatory treatment, such as increased

premiums, if their disability or chronic medical conditions interfere with their participation in employer-based health and wellness programs or achievement of a benchmark of success for a given program. We recognize that the Senate bill attempted to make accommodations for people with disabilities and chronic health conditions in these programs, but we are concerned about forcing people to disclose private health information to their employers in order to qualify for these accommodations, particularly since the accommodations have nothing to do with their ability to perform their job.

The following are specific areas of priority for the disability community:

Long-Term Services and Supports

The Community First Choice Option (CFC Option)

Policy: The CFC Option is a Medicaid State Plan Option that will allow states to give people with disabilities and older Americans eligible for institutional services an equitable choice to receive community-based long-term services and supports under Medicaid. As an incentive for states to select this option, the bill provides a 6% increase in the FMAP for the services included in the CFC.

Section 2401 of the Senate bill provides a detailed program for the CFC Option while the House bill (section 1739A) only provides a "Sense of Congress" provision. We support the language of the Senate bill and urge its adoption in the final bill.

Community Living Attendant Services and Supports (CLASS) Program

Policy: Americans with and without disabilities should have options to voluntarily plan for future long-term services and supports needs without requiring them to impoverish themselves to qualify for Medicaid.

Both the Senate and House bills include the creation of a new voluntary Community Living Attendant Services and Supports program, which would provide a new funding stream and an alternative to Medicaid that individuals could pay into from the moment they start working and that they could tap into if and when they acquire a disability and need long-term services and supports. We see this as an innovative and important program and support including it in the final health reform legislation.

Maintenance of Effort Requirements to Accompany Expanded Medicaid Eligibility

Policy: Medicaid eligibility should be expanded with safeguards in place that preserve current home and community-based benefits for individuals with disabilities.

The House bill calls for an increase in eligibility for the Medicaid program to 150% of the federal poverty level, while the Senate bill includes an increase of up to 133%. Disability advocates are concerned that if the federal government mandates that states provide Medicaid to more people, then once the 100% FMAP expires or if states incur immediate additional costs for these newly eligible individuals, states will

cut optional services, such as home and community-based services to finance the basic mandatory benefits for the newly eligible individuals.

We support the expansion so that more individuals with disabilities are covered but urge additional language to protect existing Medicaid optional community long-term services and supports. The additional language will assure that people with disabilities and older Americans are not unnecessarily forced into nursing homes and other institutions. It would allow them the the cost-effective provision of Medicaid-funded long-term services and supports in less expensive home and community settings instead of forcing them into costly institutions. This would also encourage states to comply with the US Supreme Court's Olmstead Decision and the right to receive services in "the most integrated setting."

Health Disparities

Policy: Individuals with disabilities have faced significant health disparities according to the limited available health indicators. Legislation aimed at reducing health disparities should include reducing health disparities in individuals with disabilities and chronic conditions.

The Senate's version, H.R. 3590 (Section 931), incorporates Section 485E of the Public Health Service Act to define "Health Disparity Populations." Section 485E does not specifically include individuals with disabilities or chronic medical conditions. The House' version, H.R. 3962 (Section 2301), specifies that a health disparity population may be delineated by disability. We would prefer the House's version of the definition of health disparities. If the final bill includes the House's definition of health disparities populations, we would support the balance of the Senate's health disparities policies. Though the definition is limited in Section 931, Section 1646 of the Senate's version describes a rich data collection program integrated with quality reporting requirements and programs to collect and evaluate data on disparities in health care services and performance for persons with disabilities and other populations. We support Section 1646 in the Senate version.

Data Collection

Policy: In order to decrease the health disparities faced by individuals with disabilities and improve the quality of their health and health care as a population, aggregate data must be collected that informs policy makers of the nature, extent, and possible causes of the health disparities.

The House bill Section 241 establishes the Health Choices Administration (HCA). Section 242 assigns the Commissioner of the HCA specific duties including collecting data to promote quality and value, and address disparities in health and healthcare. Section 2402 of House's version establishes an Assistant Secretary for Health Information responsible for collecting, facilitating the collection, and developing standards for the collection of data regarding the nation's health. Neither Section 242 nor Section 2402 specifically mentions collecting data on the population of people with disabilities.

Section 4302 of the Senate's version specifies that the data must be collected by disability status (among other factors), shared with numerous agencies within HHS, and evaluated for disparities in healthcare services and performance. The data collected in Section 4302 will provide policy makers with specific information about where individuals with disabilities

access their primary care, the number of providers with accessible facilities and equipment, and the number of health care providers trained in patient care of individuals with disabilities - all data that will ultimately improve the health of people with disabilities. We prefer the Senate's provisions on data collection because it specifically addresses the health needs of people with disabilities.

Training

Policy: To reduce health disparities and improve the health of individuals with disabilities, we must increase the number of medical, dental, and other health professionals trained to meet the health care needs of people with disabilities and chronic medical conditions.

Both Section 5301 of the Senate's bill, designed to increase the number of primary health care providers, and Section 5303, which promotes the number of dentists in general, pediatric and public health dentistry, give entities priority for grants if they provide training in the care of vulnerable populations. Both sections specify individuals with disabilities as a vulnerable population. While the House bill contains similar programs for increasing primary care medical and dental care providers and other health professional (see e.g. Sections 2113 and 2115), none of the House provisions specify that individuals with disabilities or chronic medical conditions are included in the definition of "vulnerable population."

Section 5307 (Cultural competency, prevention, and public health and individual with disabilities training) of the Senate's bill provides grants to reduce health disparities by training health professionals to address the needs of individuals with disabilities. Section 5101 establishes the National Health Care Workforce Commission, which is charged with reviewing, among other topics, the health care workforce needs of special populations, specifically including individuals with disabilities. However, in the House bill, Section 2251 (Cultural and linguistic competency training for health professionals), does not include individuals with disabilities or chronic medical conditions. We urge you to include individuals with disabilities and chronic medical conditions together with cultural and linguistic competency in the final bill. Therefore, we would support the Senate's language, which specifies the needs of individuals with disabilities in cultural competence and other training programs for medical, dental, and other health professionals.

Coverage Issues

Hearing-related Services

Policy: Coverage for hearing-related services and devices is needed to ensure that children have the opportunity to access sounds, spoken language and communication.

The House bill specifically identifies "hearing services, equipment, and supplies for children under 21 years of age" as essential benefits. The legislation passed in the Senate does not. We support the House version and urge its inclusion in final legislation.

We also support including language that would encourage similar coverage for about 36 million adults with hearing loss. Hearing loss that is not appropriately addressed can affect an individual's personal safety, health, independence, employment opportunities, emotional well-being, family and other social relationships.

Autism Interventions

Policy: The definition of behavioral interventions provided in the essential benefits section should specify a positive approach to behavioral interventions as opposed to aversive interventions. Research shows a high utilization of aversives, or the use of pain as a means of behavioral modification, which is why we are looking for this language change.

Both the Senate (Section 1302) and the House (Section 222) versions of the bill state that “Mental health and substance abuse services, including behavioral health treatment” should be included in the essential benefits package of all new insurance

plans. We urge that the word “positive” be inserted prior to the words “behavioral health treatment” or that report language clarify that only non-aversive interventions should be covered.

Primary Care Needs and Transitioning from Pediatric to Adult Health Care

Policy: Strengthening primary care and patient-centered medical homes must include the health care needs of individuals with disabilities and chronic conditions. Children with disabilities and chronic medical conditions need seamless health care as they transition to young adulthood. Legislation aimed at providing support to young people transitioning to adult care should support the need for competent primary care providers that can meet the health care needs of individuals with disabilities and chronic conditions.

Section 3502(c)(7)(E) of the Senate bill, designed to provide grants for community health teams to support the patient-centered medical home, prioritize chronic illness, and specify 24 hour care management and support for adolescents transitioning to adulthood. The House bill is silent. We support Section 3502 (c)(7)(E) of the Senate version. We suggest the addition of two clarifications: coordinated services between pediatric and adult health care; and training young people to self-manage their own health.

Section 5301 of the Senate bill provides grants to train primary care providers and prioritizes chronic care management and transitions of vulnerable populations. It does not include Med-Peds (combined Internal Medicine and Pediatrics), or psychiatrists (rehabilitation physicians), often the only primary care providers capable of caring for children with disabilities and chronic medical conditions throughout the life span and often the only providers capable of training other primary care providers to transition young people with disabilities and chronic medical conditions into adulthood. Section 5501(a) expands access to primary care services but does not include Med-Peds or psychiatrists. Section 2213 and 2214 of the House bill provide grants to expand and train the primary care workforce with a priority on those with health disparities or special health care needs, but it does not include Med-Peds or psychiatrists. We support the Senate version and urge you to include Med-Peds and psychiatrists as part of the primary care workforce needs of children and adults with disabilities and chronic medical conditions.

As you finalize health care reform, the undersigned supporters of JFAAN urge you to consider the policies outlined above and their impact on the health needs of more than 50 million Americans with disabilities and chronic conditions. Thank you for your leadership in getting our country so close to a historic achievement in improving access to health care.

President Obama, Speaker Pelosi and Majority Leader Reid
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Sincerely,

ADAPT
American Association of People with Disabilities
Autistic Self-Advocacy Network
Hearing Loss Association of America
Little People of America
National Association of the Deaf
National Council on Independent Living
Not Dead Yet
Self Advocates Becoming Empowered
United Spinal Association