



THE ARC, AAIDD, AUCD,
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FACT SHEET

Health Care Reform: Key Disability Issues

Background

There is broad consensus that America's health care system needs reform. Over 46 million Americans are uninsured and more join their ranks every day as unemployment rises. A March 2009 U.S. Department of Health and Human Services report which summarized several studies found that U.S. health care spending doubled from 1996 to 2006, reaching \$2.2 trillion in 2007, nearly double the average of other developed countries. All stakeholders agree that reform must provide affordable coverage, improve quality and lower costs. To achieve these goals, emphasis has been given to prevention to transform our health care system's focus from sickness to wellness, care coordination, chronic disease management, and shifting payment rates to focus on performance rather than services provided. Many Members of Congress have focused on the need to address the national shortage of physicians, nurses, and dentists which is especially severe in rural areas.

Reform must address the health care disparities faced by individuals with developmental disabilities. According to the 2002 U.S. Surgeon General's report, *Closing the Gap: A National Blue Print to Improve the Health Care Needs of Persons with Mental Retardation*. These individuals experience poorer health and have less access to medical care than the general population. People with developmental disabilities often have difficulty recognizing and communicating their own health care needs. Moreover there is a significant shortage of qualified, trained health care professionals who are willing to treat them.

In addition to improving access to quality medical care for persons with developmental disabilities, health reform legislation must improve the way our nation provides long term services and supports (such as assistance and supervision with activities of daily living, taking medication, managing a home, and preparing meals, managing money). Removing Medicaid's institutional bias so that persons with disabilities can receive services in community-based settings that are preferred and more cost-effective rather than in large congregate settings is critical. Huge waiting lists for long term services and supports across the country constitute a major crisis.

Advocates in the disability and aging communities have urged the inclusion of long term services and supports in health care reform. The effort should be two-pronged: 1) there should be a national long term services insurance program which assists eligible individuals and their families to meet long term needs with a cash benefit and without forcing them into poverty to receive Medicaid benefits; and 2) the current Medicaid program should be improved to eliminate the institutional bias and allow a real choice for the individual to receive needed services at home or in the community. Two recently introduced policy proposals would address these issues and should be incorporated in healthcare reform: the Community Living Assistance Services and Supports (CLASS) Act and the Community Choice Act (see separate Fact Sheets on these bills).

Action Taken by Congress

During a March White House Health Reform Summit, President Obama stated that health care reform is essential to achieving economic recovery. Summit attendees, including both Republican and Democratic Members of Congress, the insurance industry, health care providers, and consumer groups, agreed that achieving health care reform this year is a necessary and bipartisan priority.

President Obama has set forth general principles for reform but Congress, not the Administration, will be developing legislation. Several Congressional Committees with jurisdiction over health reform issues have held numerous hearings and have set an ambitious goal of House and Senate passage before the August recess. However, there is no consensus on many significant issues such as whether a public plan should be included and how to pay for overall reform.

The President's FY 2010 budget outline includes a reserve fund of more than \$630 billion over 10 years to finance a down payment on comprehensive health reform. The House and Senate Budget Resolutions include funding for this reserve fund; however, offsets will be required to comply with Congressional PAYGO (pay-as-you-go) rules. The House and Senate must also resolve the issue of whether the final resolution will contain reconciliation instructions on how the Senate deals with its health reform bill. Reconciliation would allow the Senate to avoid any filibuster by the minority and require only 51 votes, rather than the usual 60 votes, to pass health care reform. If reconciliation is in the Budget Resolution, a bipartisan approach to health care reform will prove more difficult. Nevertheless, health reform might be expedited if the Senate only needs 51 votes to move it forward.

Recommendations

Support health reform legislation that:

- Ensures that the private insurance system covers ALL Americans so that Medicaid and Medicare are not the only option for coverage of people with disabilities;
- Incorporates long term services and supports by including the CLASS Act and the Community Choice Act;
- Strengthens the Medicaid program so that it provides accessible, high-quality health care services to people with disabilities enrolled in the program; and
- Increases the education of physicians and dentists by amending the Public Health Services Act to require that medical schools, dental schools, and their residency programs provide training to improve competency and clinical skills in providing care to patients with disabilities (including those with intellectual disabilities) as a condition of receiving federal funds.

Relevant Committees

Senate Finance Committee

Senate Health, Education, Labor, and Pensions (HELP) Committee

Senate and House Budget Committees

House Energy and Commerce Committee

House Ways and Means Committee

House Education and Labor Committee

For more information, please contact The Arc and United Cerebral Palsy Disability Policy Collaboration (202) 783-2229, Association of University Centers on Disability (301) 588-8252, American Association on Intellectual and Developmental Disabilities (202) 387-1968, National Association of Councils on Developmental Disabilities (202) 506-5813 or the Self Advocates Becoming Empowered (802) 760-8856.

2009 DISABILITY POLICY SEMINAR

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TALKING POINTS FOR ADVOCATES

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HEALTH REFORM

- People with intellectual and developmental disabilities don't want to live in institutions. They want to live in the community so they can work, go to social activities like everyone else.
- Institutions cost a lot of money to run and they are not good places to live. It is much less expensive for the government if people with intellectual and developmental disabilities live in the community.
- People with intellectual and developmental disabilities have a great deal of trouble finding a doctor or a dentist because Medicaid doesn't pay doctors and dentists enough and medical and dental schools don't train medical and dental students about how to treat a person with an intellectual or developmental disability.
- It is often hard for people with intellectual and developmental disabilities to communicate with a dentist or a doctor. *(tell stories you have heard about this)*.
- People with intellectual and developmental disabilities are getting older. There are few prevention and wellness programs for them.

Congress should:

- Change Medicaid so that people with intellectual and developmental disabilities can live in the community instead of in institutions;
- Change the law so that doctors and dentists have to learn about treating patients with intellectual and developmental disabilities when they are in medical or dental school; and
- Change the law so that everyone with a disability has good health care.

4/13/09

