



Health Care & Long Term Services Reform: Issues for People with Intellectual and Developmental Disabilities

The Case for Reform

There is broad consensus that America's health care system needs reform. Health care spending doubled from 1996 to 2006, reaching \$2.2 trillion in 2007, nearly double the average of other developed countries. Yet, over 46 million Americans are uninsured and we have poorer health outcomes than other industrialized countries.

All stakeholders agree that reform must provide affordable coverage, improve quality and lower costs. For people with intellectual and developmental disabilities (IDD), the need for health and long term care reform is especially urgent for a number of reasons:

- **Setting.** Medicaid's institutional bias makes it difficult for persons with disabilities to receive services in community-based settings. This has resulted in over 300,000 people on waiting lists with average waits of 8-10 years for home and community based services.
- **Coverage.** Under current law, private insurance companies in the individual and small group markets are allowed to exclude persons with pre-existing conditions from coverage and "cap" annual and lifetime coverage, policies which disproportionately impact people with disabilities.
- **Benefits.** People with disabilities often need rehabilitation and habilitation services as well as durable medical equipment (such as wheelchairs and augmentative communication devices), prosthetics, and orthotics. These services and products are covered in all public and some private health plans. They must be covered in any new plans developed as part of health care reform.
- **Access to Quality Care.** Our constituents experience poorer health and have less access to quality medical care for a number of reasons including low Medicaid reimbursement rates, the shortage of qualified health care professionals who have received training in how to treat people with IDD, and inaccessible medical equipment.
- **Long Term Services and Supports.** Our current health care system is principally designed to meet the country's short term or "acute" care needs. Our constituents often need assistance with activities of daily living throughout their lifetimes, such as getting dressed, taking medication, preparing meals, and managing money. Only 3% of Americans have private long term care (LTC) insurance due to its high costs and Medicare provides only very limited LTC coverage. This leaves the overburdened and institutionally biased Medicaid program as the primary provider of LTC.



The Arc and UCP's Policy Priorities

The Arc and UCP have developed very specific recommendations as part of the Consortium for Citizens with Disabilities (CCD), the coalition of over 100 national disability organizations. We have responded to the options and plans that have been released to date by Congressional Committees. Our highest priority recommendations include:

Setting

- Allowing states to offer additional services under the 1915(i) Medicaid Home and Community-Based Services (HCBS) waivers State Plan Option.

Coverage

- Prohibiting private health insurance exclusions for pre-existing conditions.
- Restricting the consideration of health status in setting premiums.
- Expanding Medicaid to cover individuals with incomes up to 133 percent of the federal poverty line (approximately \$29,000 per year for a family of four).

Benefits

- Ensuring that minimum covered benefits include products and services that enable people with disabilities to maintain and improve function, such as rehabilitation and habilitation services and durable medical equipment (such as wheelchairs and augmentative communication devices) and prosthetics and orthotics.

Access to Quality Care

- Increasing Medicaid provider rates to the levels of Medicare providers.
- Requiring training of physicians, dentists, and allied health professionals on how to treat persons with disabilities.
- Integrating health disparities based on disabilities on the same basis as racial and ethnic disparities.
- Ensuring prevention programs include a focus on individuals with disabilities.

Long Term Services and Supports

- Increasing the federal share of Medicaid, known as the federal Medical Assistance Percentage (or FMAP) for HCBS and during periods of economic downturn.
- Strengthening long-term services and supports through a two pronged approach:
 - 1) Make program improvements within Medicaid by including the [Community Choice Act](#) which would provide for personal attendant services; and
 - 2) Establish a national voluntary program to finance long-term services and supports by including the [Community Living Assistance Services and Supports \(CLASS\) Act](#) that will also relieve pressure on the Medicaid program.

For more information, contact the Disability Policy Collaboration of The Arc and UCP at 202-783-2229.