



THE ARC, AAIDD, AUCD,  
UCP, NACDD AND SABLE

## FACT SHEET

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### LONG-TERM SERVICES AND SUPPORTS

#### **Background**

In addition to expansion of community-based long-term services and supports through the Community Choice Act and the Community Living Services and Supports Act (CLASS) Act (see separate fact sheets), there are other important improvements needed. Three of these include: 1) increased wages for direct support professionals; 2) improvements to the Medicaid Home and Community-Based State Plan Option; and 3) removal of the two-year waiting period for Medicare for individuals with disabilities eligible for Social Security Disability Insurance (SSDI).

#### **Direct Support Professionals Fairness and Security Act**

For millions of individuals with disabilities of all ages, direct support professionals are the key to living successfully in their home communities. Direct support professionals are personal care assistants, home care aides, or staff in community residential supports programs that assist individuals with disabilities. Unfortunately, there is a crisis in the availability of professionals to provide these direct supports. This crisis is in partially a result of low wages and poor benefits these workers receive. As a result, individuals with disabilities often experience continuous turnover of direct support workers or they find themselves unable to get workers at all. Unable to obtain adequate assistance, people find their health, safety, and sometimes, their lives in jeopardy.

Representatives Lois Capps (D-CA) and Lee Terry (R-NE) introduced the Direct Support Professionals Fairness and Security Act (H.R. 868). The bill would take important steps to ensure that direct support professionals are paid wages and benefits that enable them to stay in their jobs and provide the critical services that people with disabilities rely upon. The bill would amend the Medicaid program to provide funds to States to enable them to increase the wages paid to targeted direct support professionals in providing services to individuals with disabilities. The program is designed as an option to states and would provide enhanced federal medical assistance percentage (FMAP) for five years to states to increase wages. In order to receive the enhanced FMAP, states would be required to submit a five-year plan and would have to assure continuation of the increased wage rate after the five-year period. The state plan must be developed in conjunction with individuals with disabilities and family members, private providers, and direct support professionals.

#### **Improvement to Home and Community-Based Services State Plan Option**

The Deficit Reduction Act of 2005 (DRA) established a new Medicaid Home and Community Based Services state plan option. The 1915(i) option allows states to provide home and community-based services (HCBS) without requiring that states use a waiver process. To add this new option to its state Medicaid plan, a state would have to file a Medicaid state plan amendment. The new option also requires states to establish stricter eligibility criteria (level of care) for institutional services than for community-based services. For the first time, a state will be able to offer HCBS services to people who would not otherwise qualify for the institutional services in that state.

While the new option has many good features, there are some limitations in the way it was drafted which have resulted in few states adopting the option. The following improvements are needed to the HCBS option:

- Remove the authority for states to cap services and maintain waiting lists;
- Allow states to provide the full range of services that can currently be provided under the HCBS waiver (including other services approved by the Secretary);
- Remove the limit on coverage of people with incomes up to 150 percent of poverty and allow the full range of income eligibility allowed for people in facility-based settings; and
- Eliminate the states' ability to limit services to certain sections of the state.

Senators Kerry (D-MA) and Grassley (R-IA) introduced the Empowered at Home Act (S. 434) on February 13, 2009. Sections of this legislation would make the improvements outlined above and establish incentives for states to take up the option.

### **End the Medicare Two-Year Waiting Period**

In the United States, nearly 7 million people under age 65 qualify for Medicare due to severe and permanent disabilities. However, these individuals with disabilities must wait two years after they are deemed eligible for Social Security Disability Insurance (SSDI) to receive Medicare coverage. As a result, there are as many as 1.5 million men and women who are too disabled to return to work but who must wait to receive Medicare coverage at a time when they likely most need health care. Nearly 39 percent are uninsured for at least some of the time during the waiting period, and 26 percent have no insurance throughout the waiting period. This policy devastates families financially, contributes to the development of preventable secondary conditions, worsening of health status, and death for some individuals.

Senators Jeff Bingaman (D-NM), Sherrod Brown (D-OH), and Susan Collins (R-ME) introduced the Ending the Medicare Disability Waiting Period Act of 2009 (S. 700). Representatives Gene Green (D-TX) and Lee Terry (R-NE) introduced a companion bill in the House (H.R. 1708). This legislation would gradually phase out the two-year waiting period for Medicare.

### **Action Taken by Congress and the Administration**

The Direct Support Professionals Fairness and Security Act (H.R. 868), Empowered at Home Act (S. 434), and the Ending the Medicare Disability Waiting Period Act (S. 700/H.R. 1708) have been reintroduced.

### **Recommendations**

Members of Congress should co-sponsor these bills and work towards passage as stand-alone legislation or as part of comprehensive health care reform.

### **Relevant Committees**

Senate Finance Committee

House Energy and Commerce Committee (Subcommittee on Health)

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.

4/13/09

## TALKING POINTS FOR ADVOCATES

### FOR YOUR USE ONLY/NOT FOR DISTRIBUTION

#### LONG-TERM SERVICES AND SUPPORTS

- There is a crisis in the availability of direct support professionals. Individuals with disabilities and their families experience difficulty finding and keeping direct support workers to provide long-term services.
- Low wages and benefits contribute to high turnover which puts the health and safety of individuals with disabilities at risk.
- Representatives Lois Capps (D-CA) and Lee Terry (R-NE) introduced the Direct Support Professionals Fairness and Security Act (H.R. 868) to assist states with improving wages of direct support professionals.
- The Medicaid Home and Community Based state plan option was passed to help expand home and community based services, but improvements are needed to encourage states to use it.
- Senators Kerry (D-MA) and Grassley (R-IA) introduced the Empowered at Home Act (S. 434). Part of this bill would make the needed improvements.
- Individuals with disabilities under age 65 must wait two years after they are eligible for Social Security Disability Insurance (SSDI) to receive Medicare.
- While waiting for health insurance through Medicare, families go bankrupt, the health of individual with disabilities worsens, and many people die.
- Senators Bingaman (D-NM), Brown (D-OH), and Collins (R-ME) and Representatives Green (D-TX) and Lee Terry (R-NE) introduced the Ending the Medicare Disability Waiting Period Act (S. 700/H.R. 1708). This bill would gradually phase out the two-year waiting period for Medicare.

#### Congress should:

- Pass the Direct Support Professionals Fairness and Security Act (H.R. 868), sections of the Empowered at Home Act (S. 434) concerning the Medicaid state plan option, and the Ending the Medicare Disability Waiting Period Act (S. 700/H.R. 1708) as part of health reform.

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