



A Partnership of The Arc &  
United Cerebral Palsy

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## FISCAL YEAR 2006 APPROPRIATIONS PROCESS MOVING QUICKLY

The 109<sup>th</sup> Congress is moving ahead on a number of appropriations bills that will determine federal spending for Fiscal Year 2006, beginning October 1, 2005. The House of Representatives has passed all eleven of its FY 2006 appropriations bills while the Senate has completed action on six of its twelve appropriations bills. The Senate Appropriations Committee has cleared the way for its final six bills, which now await final action on the Senate floor.

Of greatest interest to The Arc and United Cerebral Palsy are the appropriations bills for the Departments of Labor, Health and Human Services and Education and the Departments of Transportation, Treasury and Housing and Urban Development. These bills fund practically all federal discretionary spending for disability programs. The Senate has finalized neither bill. The table on the next page compares funding for key disability programs with current (FY 2005) funding levels, the Bush Administration's request, the House and Senate bills and the Disability Policy Collaboration recommendations (\*\*Senate figures reflect Appropriation Committee actions).

*Monthly information related to mental retardation, cerebral palsy and other disabilities*

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## Appropriations Recommendations for FY 2006 (in millions)

DEPARTMENT OF LABOR	FY 2005 Final	FY 2006 President	FY 2006 House	FY 2006 Senate	FY 2006 DPC
Workforce Investment Act					
Adult Employment	898.1	866.0	865.7	893.6	987.9
Pilots, Demonstrations, Research	85.8	151.0	74.0	90.4	151.0
Youth Activities	994.0	950.0	950.0	986.3	1093.4
Office of Disability Employment Policy	47.5	28.0	27.9	47.2	47.5
Work Incentives Grants	19.7	19.7	19.7	19.7	20.7
DEPARTMENT OF HHS					
Developmental Disabilities Programs					
Basic State Grants – Councils on DD	72.0	72.0	72.5	72.5	77.0
Protection & Advocacy Systems -- DD	38.0	38.0	38.1	39.1	45.0
University Centers for Excellence in DD	31.5	31.5	33.5	33.5	37.0
Projects of Nat'l Significance & Family Support	11.0	11.0	11.5	11.5	22.6
Maternal & Child Health Block Grant	724.0	724.0	700.0	710.0	755.0
Centers for Disease Control & Prevention					
Birth Defects, D.D., & Health	124.0	124.0	127.2	125.8	135.0
Chronic Disease Prevention	899.0	840.0	856.5	860.6	899.0
National Institutes of Health					
Natl. Institute of Child Health and Human Development	1,270.0	1,350.0	1,277.5	1,311.0	1,367.5
Natl. Institute of Neurological Disorders & Stroke	1,539.0	1,550.0	1,550.0	1,591.9	1,650.0
Social Services Block Grant	1,700.0	1,700.0	1,700.0	1,700.0	2,380.0
Child Development Block Grant	2,082.9	2,082.9	2,082.9	2,082.9	2,588.0
Protection & Advocacy for Voting Access	4.9	4.9	4.9	4.9	10.0
State Grants - Remove Barriers to Voting	9.8	9.8	9.8	9.8	25.0
DEPARTMENT OF EDUCATION					
IDEA					
State and Local Grants Part B	10,589.7	11,097.7	10,739.7	10,689.7	14,649.0
Preschool Grants	384.6	384.6	384.6	384.6	422.0
Early Intervention Part C	440.8	440.8	440.8	444.3	485.0
Personnel Preparation	90.6	90.6	90.6	90.6	108.7
Parent Information Centers	26.0	26.0	26.0	26.0	28.6
Transition	n/a	5.0	0.0	0.0	5.5
Rehabilitation Services Administration					
Rehabilitation State Grant	2,635.8	2,720.2	2,720.2	2,720.2	2,990.2
Rehabilitation Training	38.8	38.8	38.83	38.83	42.7
P&A for Individual Rights	16.6	16.6	16.66	16.66	22.0
Supported Employment State Grant	37.7	0	30.0	30.0	41.4
Natl. Institute for Disability & Rehabilitation Research	107.8	107.8	107.8	107.8	110.0
Assistive Technology Act Programs	29.8	0	29.8	30.3	31.0
P&A for Assistive Technology	4.4	0	4.4	4.5	6.0
DEPARTMENT OF HUD					
Section 811 Supportive Housing	238.0	120.0	238.0	240.0	238.0

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Hamstrung by a very conservative FY 2006 Budget Resolution, which provides essentially no increase for human services spending for the next fiscal year, appropriators in both Houses were pressed to eke out increases for a few disability programs. Unfortunately, other disability programs felt the budget ax and were cut, frozen or only received small increases.

The Congress rejected attempts by the Bush Administration to eliminate programs, such as new housing starts under the HUD Section 811 program, the Assistive Technology State Grant and the Supported Employment State Grant program. The Senate bill adds a bit more funding for some programs, but only by using a gimmick—that is, the bill would free up over \$3 billion by delaying the last SSI payment for a few days so that the payment is actually charged to the next fiscal year. A similar gimmick was attempted last year, but the ploy was rejected in conference.

Highlights for key disability program funding include:

- A \$150 million increase in the House bill for the IDEA State Grant program while the Senate bill would appropriate only an extra \$100 million. This compares most unfavorably with the more than \$1 billion average increase for the program over the past half dozen years.
- Both bills cut the Supported Employment State Grant program by almost \$8 million, but reject the Administration's request to eliminate this \$38 million program.
- DD Act programs are frozen or given small increases.
- The House bill freezes the Tech Act while the Senate increases it by \$500,000.
- The Senate bill makes a very small cut in the Department of Labor's Office of Disability Employment Policy while the House bill parallels the Administration's request to cut the program by 40 percent.
- Both bills reject eliminating the portion of HUD's Section 811 Assistive Housing program for new housing starts.

The Senate is not scheduled to complete action of the remaining appropriations bills until returning to work after Labor Day. Given that the two bills funding disability programs are among those usually done last and the extraordinary tight Senate schedule in September, preliminary rumors have already surfaced that Congress may need to bundle a number of appropriations bills into a large omnibus bill.

Completing all appropriations bills before October 1 would mean Congress would have to drop other “must do” legislation that must be completed before the start of the new fiscal year. Only time will tell when the appropriations process will be completed and how disability programs will fare after the House and Senate leadership resolve the differences between their respective bills.

## HHS MEDICAID COMMISSION'S FIRST MEETING OUTLINES CRITICAL DEADLINES AND KEY ISSUES

The U.S. Department of Health and Human Services' (HHS) Medicaid Commission (the voting and non-voting members) held its first public meeting on July 27, beginning discussions about how to generate \$10 billion in savings from the Medicaid program over the next five years. The Disability Policy Collaboration, health care advocates, provider groups and others with a stake in Medicaid turned out for this all-day meeting, with a two-hour window for public participation.

Former Tennessee Governor Don Sundquist and former Maine Governor Angus King, the Commission's co-chairs, called the sparsely attended meeting and HHS Secretary Michael Leavitt opened with his statement. Leavitt acknowledged the Commission's late start will force it to limit its analysis of how the \$10 billion in Medicaid savings will be achieved. He also urged the Commission to sort through reform proposals submitted by other groups.

In his initial comments, Chairman Sundquist announced that the Commission would vote on recommendations to generate the \$10 billion in savings from the program at its mid-August, two-day meeting, with a report due to HHS Secretary Leavitt by September 1.

For the next few hours, the 26 Commission members introduced themselves to the audience and then listened to the "Background on Medicaid" presentation by the National Association of State Medicaid Directors and McKinsey and Company, a health care consulting company.

Members of the Commission were given the opportunity to make comments about the presentation and provide their own views of the Medicaid program. Many Commissioners raised the importance of guaranteeing health care coverage to children while others discussed the need for individuals to purchase long-term care insurance offered by private insurance plan – a method of taking "personal responsibility" for health care (another example of personal responsibility discussed was increasing cost-sharing for beneficiaries). The Commissioners and some public commenters raised the importance of Early and Periodic Screening, Diagnosis and Treatment (EPSDT), currently a mandatory Medicaid benefit.

The Disability Policy Collaboration was one of 14 organizations that spoke during the public comment period. The statement, offered on behalf of The Arc of the United States and United Cerebral Palsy, sought to educate the Commissioners on important distinctions between people with disabilities who receive Medicaid and other beneficiaries. At the start, the DPC refuted the commission's notion that Medicaid beneficiaries could obtain health and private, long-term care insurance, indicating that people with disabilities have very complex needs that cannot be met in the private market and that affordability and pre-existing conditions are major factors preventing these individuals from obtaining this type of insurance.

The DPC further explained that The Arc and UCP support some proposals to generate Medicaid savings, but not at the expense of beneficiaries. Commissioners were urged to reject proposals to increase state flexibility in benefit design since states already have significant flexibility in the services they provide and can define the amount, duration, and scope of the services.

The DPC requested that the Commission maintain Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) as a mandatory benefit, which is a critical Medicaid benefit that makes a huge difference in people's lives. Commissioners were told that an early investment in children could save money by enabling children to maximize their development and educational attainment while minimizing the need to receive life-long services.

Next, the DPC addressed the topic of beneficiary cost sharing and urged the Commission to reject any increases, since beneficiaries in many states live on SSI benefits of \$579 per month and often already pay out of pocket for fundamental services like dental or vision care. The DPC referred to a recent study that found that Medicaid beneficiaries with disabilities on SSI paid 8 times more in out of pocket costs, as a percentage of their annual income, than did middle class individuals with private health insurance. Moreover, many dual eligibles with developmental disabilities could face increased cost sharing for prescription drugs on January 1, 2006 when they transfer to the new Medicare Part D benefit, which will make it a difficult choice between paying for food and the heating bill or the co-pay for prescription medications.

Finally, commissioners were asked to maintain the current Medicaid provisions that protect people with disabilities or people who transfer assets to people with disabilities. The DPC stressed that for many decades, families of people with severe disabilities have used trusts in long-term planning for loved ones where parents find that the trust device allows them to continue to provide for their son or daughter after their own deaths and to supplement services provided through Medicaid and SSI. Medicaid law currently recognizes these important planning tools for people with severe disabilities and protects them from harsh penalties.

Before adjourning, Chairman Sundquist announced that the HHS staff would provide a list of proposals for Medicaid savings, including an analysis of estimated savings, before the next meeting, and asked the non-voting Commissioner from the National Conference of State Legislatures to submit recommendations. Sundquist noted that the HHS list would already include the National Governors Association's recommendations. However, it was not clear whether the HHS's Medicaid actuary or the Congressional Budget Office would develop the savings' estimates.

At the upcoming mid-August, two-day meeting, the first day will be devoted to a discussion of various proposals. Commissioners will vote on recommendations on the meeting's second day. Before this meeting, the DPC will be submitting additional details on our recommendations to the Commission.

#### CENSUS BUREAU REPORTS ON PREVALENCE OF DISABILITY AMONG AMERICAN FAMILIES

Using data from its 2000 census survey, the U.S. Census Bureau released a special report on *Disability and American Families*. The Census Bureau, which issued its report in July 2005, drew many conclusions from the data the agency collected related to the prevalence of disability in American families. The data was collected from six questions on the Census 2000 long form, which includes questions on the short form and additional questions relating to social, economic and housing characteristics. Here are the bureau's major findings from the report:

##### Disability Prevalence among Families

- Census 2000 counted a total of 72.3 million families and found that nearly 28.9 percent of them (about 2 in every 7 families) reported having at least one member with a disability.
- In 13 million families, the householder had a disability (18.0 percent of all families), and in 2.8 million families (3.9 percent of all families), children had a disability.
- Disability rates varied among single-race groups and Hispanics.
- Disability was more prevalent among families in the South and in rural areas.
- One in every three families with a female householder with no husband present reported members with a disability.

##### Economic Characteristics of Families Varied With Disability Status

- Families with members with a disability had lower median income than other families.

- Families with members with a disability were less likely than other families to have earnings and more likely to receive income from Social Security and public assistance.
- Family householders with disabilities were less likely to be employed and less likely to be in the labor force than other family householders.
  - Among householders with disabilities, those with a mental disability had the lowest employment rate, 34.2 percent, and the largest proportion of people not in the labor force, 60.8 percent.
  - Next were householders with a physical disability, with an employment rate of 39.3 percent in 2000, 56.8 percent of them did not participate in the labor force.
- The median income of families with a householder who worked full-time, year-round varied by whether the householder had a disability and by the type of disability.
- Families with householders with a disability were less likely to own their residence than other families.

### Disability and Family Poverty

- In every state, families with members with a disability were more likely than other families to live in poverty.
- Of the families with two or more members with a disability, 16.5 percent were in poverty.
- Poverty and disability tended to occur in similar proportions in Black families and American Indian and Alaska Native families.
- Families in the South had higher prevalence rates of both disability and poverty.
- The poverty rates for families with a member with a disability varied with the composition of the family and the race and Hispanic origin of the householder.

### Families Raising Children with a Disability

- One in every 26 American families reported raising children with a disability.
- Employment situations varied among householders raising children with a disability.
- Families raising children with a disability had a lower median income than other families.
- Families raising children with a disability were more likely to live in poverty than other families raising children.
- Married-couple families raising children with a disability were better off economically than other families raising children with a disability.

The U.S. Census Bureau's special report, *Disability and American Families*, has many useful national and regional statistics on people with disabilities and their families. For chapters of The Arc or affiliates of United Cerebral Palsy, this information could be utilized in reports, grant applications, brochures, news releases and other news-related items to highlight the prevalence of disability in American families and the economic status of these families.

The DPC encourages all executives and advocates to check out this report, which the U.S. Census Bureau Web site has posted its Web site at <http://www.census.gov/prod/2005pubs/censr-23.pdf>, and pass it along to others who may find it helpful.

## NEW SOCIAL SECURITY SECTION 301 RULES HELP PROTECT PEOPLE WITH DISABILITIES

For people with disabilities who are 18 to 64 years old and receive Social Security or Supplemental Security Income (SSI) disability benefits, the Social Security Administration (SSA) issued new regulations on June 24, 2005 improving the Social Security Act's process and protections for people who are determined "no longer disabled." The new regulations are especially important to young people with disabilities, encouraging them to stay in school and get the necessary education and vocational training to live more independently as adults. It is useful to know how advantageous these protections can be should SSA ever make a determination that a person's impairment is no longer disabling.

### Congress Creates Social Security Exemption for Voc Rehab Training - The "301" Program

In 1980, Congress passed a law that allowed persons with disabilities to continue receiving Social Security and Supplemental Security Income (SSI) benefits for a limited period of time, even if the SSA determined that the person's condition was no longer disabling. The key factor for allowing persons with disabilities to continue receiving benefits is their participation in a vocational rehabilitation program, which will increase the individual's likelihood for permanent removal from Social Security or SSI. The process, which stems from "Section 301" of the 1980 Social Security law, is referred to as "301 regulations."

Congress expanded the Section 301 provision three times since the 1980 law. In 1987, Congress made clear that the 301 disability provisions also apply to people who receive SSI due to blindness. In 1990, Congress extended the protection to individuals who participate in approved non-state vocational rehabilitation programs. Finally, in 1999, Congress expanded the list of possible providers to include providers of "vocational rehabilitation services, employment services, or other support services" as part of the Ticket-to-Work and Work Incentives Improvement Act of 1999.

What are the new 301 regulations?

Aside from updating the regulations to include Congress's expansion of the 301 provisions, the new 301 regulations also clarify how SSA will apply the rules in the redeterminations conducted when a child beneficiary turns 18. SSA's new regulations more adequately address the reality of the lives of young people with severe disabilities who receive SSI disability benefits as children.

How do the new rules work?

Under the new 301 rules, for payments to continue after SSA has determined that the SSI or Social Security disability beneficiary's medical condition is no longer disabling, two conditions must be met:

- The person must be participating in an "appropriate" vocational rehabilitation services, employment services, or other support services program that meets SSA's specifications, before the date that SSA determines the person's disability ended; and
- SSA must make the determination that continuing to participate in the activity will improve the person's likelihood of being permanently removed from the disability rolls.

The new regulations provide further details on what an “appropriate” program is, how SSA defines participation in such a program, what a “likelihood” determination is, and what benefits continue if a person is eligible for 301 protections and when these protection will end.

SSA also clarifies that young people ages 18 to 21 who are participating in an Individualized Education Program (IEP) and the subsequent transition services (under the Individuals with Disabilities Education Act) may meet the requirements for an “appropriate program” and the “likelihood” determination. As a result of this clarification, young SSI beneficiaries who are found to be “no longer disabled” may be allowed to continue receiving critical SSI support by remaining in school to complete their IEP and/or transition programs.

New regulations took effect on July 25, 2005

The regulations are of significant benefit to some individuals who would otherwise lose their benefits should SSA make a determination that they are no longer disabled. The notice of the final regulation can be found at: <http://a257.g.akamaitech.net/7/257/2422/01jan20051800/edocket.access.gpo.gov/2005/pdf/05-12432.pdf>.

#### CONGRESS TAKES SIGNIFICANT STEPS TOWARD RESTORING SECTION 811 FUNDING

The House of Representatives restored \$118 million to the Section 811 Supportive Housing for Persons with Disabilities Program in its FY 2006 Transportation, Treasury, and Housing and Urban Development (HUD), the Judiciary and District of Columbia appropriations bill (H.R. 3058) on June 30. H.R. 3058 funds Section 811 at \$238 million – its FY 2005 level.

The leadership of Rep. Joseph Knollenberg (R-MI), chairman of the House Transportation, Treasury, Housing and Urban Development (HUD) and Judiciary Appropriations Subcommittee, was instrumental in the restoration of this funding. Chairman Knollenberg was also instrumental in directing HUD to use all of the \$118 million for production of new units, rather than Section 811 Mainstream vouchers. It is estimated that this amount will fund approximately 1,500 new units next year.

The Bush Administration’s FY 2006 budget recommended that \$118 million (or 50 percent of the program’s total funding) be cut from the program, which would have eliminated new affordable housing unit production. The Section 811 program is the only federal housing program that builds affordable and accessible housing with the supportive services for people who have severe disabilities and the lowest incomes. In many areas, it is the only community-based alternative for these individuals.

Shortly after the House action, the Senate Appropriations Committee also approved its Fiscal Year 2006 Transportation, Treasury, the Judiciary, HUD and Related Agencies appropriations bill, including \$240 million for Section 811. In addition to restoring the \$118 million, Sen. Christopher “Kit” Bond (R-MO), chairman of the HUD Appropriations Subcommittee, increased the funding for new unit production by \$2 million. The Senate bill also shifts Section 811 mainstream vouchers to the Section 8 Housing Choice Voucher program’s tenant-based renewal account, an effort advocated by disability groups to prevent the depletion of Section 811 new construction funds by increasing voucher renewals. The full Senate’s vote is expected in September—followed by a House-Senate Conference to resolve differences in the overall bill.

Restoring the funding for the Section 811 production program is a high priority for The Arc and United Cerebral Palsy and other organizations representing persons with significant disabilities.