



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

**The Consortium for Citizens with Disabilities
Fiscal Year 2009 Appropriations Recommendations
for Selected Federal Programs of Importance to
Individuals with Disabilities**

April 2008



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INTRODUCTION

The Consortium for Citizens with Disabilities is a coalition of national consumer, advocacy, provider and professional organizations headquartered in Washington, D.C. (A list of members is available at www.c-c-d.org) Since 1973, CCD has advocated on behalf of people of all ages with physical and mental disabilities and their families. CCD has worked to achieve federal legislation and regulations that assure that the 54 million children and adults with disabilities are fully integrated into the mainstream of society.

CCD does this by:

- Identifying and researching public policy issues, developing testimony and policy recommendations and encouraging innovative solutions to public policy concerns;
- Educating members of Congress in an effort to improve public policies and programs that foster independence, productivity, integration and inclusion of people with disabilities; and
- Encouraging people with disabilities and their families to advocate for themselves and coordinating grass roots efforts to support these advocacy efforts.

CCD's Vision

CCD envisions an American society in which all individuals, aided by an enabling government, have the freedom and opportunity to exercise individual decisions concerning their own lives, welfare and personal dignity.

CCD envisions a society in which communities are fully accessible to all individuals with disabilities and their families, where they are included and fully participate in all aspects of community life.

In CCD's vision of society, individuals with disabilities exercise their full rights and responsibilities.

CCD's Mission

To achieve this vision, CCD engages in advocacy efforts for national public policy that:

- Ensure the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society;
- Enhance the civil rights and quality of life of all people with disabilities and their families; and
- Reflect the values of the Americans with Disabilities Act

The State of the Nation -- Disability in the U.S.

At the dawn of the 21st Century, a number of laws stand to protect, provide for, and assist people with disabilities. Some are longstanding entitlements, such as Social Security cash benefits and Medicaid and Medicare health care and long term services and supports. Some provide for innovative approaches, such as the Assistive Technology Act of 1998. Some protect and provide services for children and families, such as Child Abuse Prevention and Treatment Act.

Other laws stand to protect rights. The Individuals with Disabilities Education Act (IDEA) protects the rights of children with disabilities to obtain a free and appropriate public education. The Fair Housing Amendments Act (FHA) protects against discrimination in Housing. The Air Carrier Access Act (ACAA) protects against discrimination in air transportation. The Rehabilitation Act protects against discrimination in employment, training and any program that receives federal funding; and the Help America Vote Act (HAVA) ensures full access to participation in the electoral processes of our country.

The Americans with Disabilities Act (ADA), written with people with disabilities, is the most comprehensive federal civil-rights statute protecting the rights of people with disabilities to date. It affects access to employment; state and local government programs and services; places of public accommodation, and telecommunications. The legal and political roots of the ADA are deep in the civil rights movement, and its legal precedent lies in two great civil rights statutes, the Civil Rights Act of 1964 and Title V of the Rehabilitation Act of 1973.

Sadly, the promises of these and many more laws that address rights and services for children and adults with disabilities often remain unfulfilled.

The 2000 U.S. Census found that there are more than 54 million Americans with disabilities. The percentage of people with disabilities is larger than any single ethnic, racial, or cultural group in the U.S. At 19.3 percent, the number of people with disabilities exceeds the next largest group by a fairly wide margin.

The 2000 U.S. Census also found that at least 16 percent of the people in each defined ethnic, racial, and cultural group also self-identified as having disabilities: 24.3 percent of both African Americans and American Indians/Alaska Natives, 20.9 percent of Latinos, 18.5 percent of Caucasians, and 16.6 percent of Asians reported disabilities.

Demographic, legal, and political forces continue to stimulate demand for disability residential and community based services in the United States. According to the State of *The States in Developmental Disabilities 2008*, The number of persons over age 65 will more than double within the next 30 years (U.S. Census, 2004). Demand for services for people with developmental disabilities who reside with

aging family caregivers will significantly increase. In 2006, for example, approximately 2.8 million of the 4.7 million persons with intellectual/developmental disabilities in the U.S. were receiving residential support from family caregivers.

The Rehabilitation Research and Training Center on Disability Demographics and Statistics (StatsRRTC) reported in 2005 that the median household income of working-age people with disabilities increased from \$34,200 in 2003 to \$34,300 in 2004, in the U.S. while the median household income of working-age people without disabilities increased from \$58,400 in 2003 to \$60,000 in 2004.

In addition, people with disabilities who are African American or Latino have even lower income levels than people with disabilities who are Caucasian. The 2003 average household income for Latinos with disabilities was \$19,000, and for African Americans with disabilities, \$10,000.

The National Organization on Disability also reports that better education is a significant factor in raising the employment and income levels of people with disabilities and that under-educating and segregating students with disabilities often produces unemployed adults, existing on government benefits because they are unprepared for the job market. Nonetheless, students with disabilities remain twice as likely to drop out of high school (21 percent versus 10 percent of students without disabilities), and only 9.5 percent graduate from college, compared to 28.5 percent of people without disabilities.

Although employment rates vary based on the severity of a person's disability, only 35 percent of people with disabilities are employed, in contrast to 78 percent of all working-age.

According to the Substance Abuse and Mental Health Services Administration (SAMHSA), about 2.2 million adolescents ages 12 to 17 (9 percent) experienced at least one major depressive episode in the past year. These adolescents were more than twice as likely to have used illicit drugs in the past month than their peers who had not experienced a major depressive episode (21.2 percent compared with 9.6 percent).

SAMHSA also reported in 2005 that one-fifth of all students receive some type of school-supported mental health services during the school year. Elementary, middle, and high schools all cite social, interpersonal, or family problems as students' most frequent mental health problems. Mental health problems are broadly defined in the new publication, "School Mental Health Services in the U.S., 2002-2003." (SAMHSA, 11/22/05)

An estimated \$100 million of taxpayers' money is spent on detention of youth awaiting community mental health services. (House Government Reform Committee Report, July 7, 2004)

An estimated 17 million adults ages 18 and older (8.0 percent) reported experiencing at least one major depressive episode during the past year. (SAMHSA Advisory, 11/18/05)

According to *Priced Out in 2006: The Housing for People with Disabilities*, the national average rent for a modest one-bedroom housing unit climbed to a record high of \$715 in 2006 – more than the entire monthly income of people with disabilities who rely on the federal Supplemental Security Income (SSI) program to pay for housing and other basic needs. In 2006, the national average income of a person with a disability receiving SSI was \$632 per month. *Priced Out in 2006* reveals that rents for modest one-bedroom units were equal to 113.1 percent of monthly SSI payments, and studio/efficiency rents were

100.1 percent of SSI during 2006 – shutting people with disabilities out of the rental market in every city, town and rural area of the country.

Finally, some 8 million working-age Americans with disabilities receive federal benefits of \$50 billion annually from Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). In 2006, the federal government estimated that if just 1 percent of people currently on SSDI went to work and no longer needed government benefits, \$3.5 billion would be saved.

Still, federal resources for critical programs to support the independence and productivity of children and adults with disabilities in the United States erode year after year; and more, not fewer, children are deprived of all of the best in a free, appropriate public education. More, not fewer, people with disabilities find it hard to get and keep gainful employment. More, not fewer, families are financially devastated by the lack of assistance with excessive health care expenses for their family member with a disability. And more, not fewer, communities are diminished by the lack of inclusion of and participation from some of their most valuable citizens, those with disabilities.

It is in the context of these facts, and on behalf of people with disabilities everywhere, that the Consortium for Citizens with Disabilities makes the following recommendations for Fiscal Year 2009 appropriations for selected federal programs relevant to people with.



Appropriations Recommendations for FY 2009 (in millions)

DEPARTMENT OF LABOR	FY 2007	FY 2008	FY 2009 President	FY 2009 CCD
Workforce Investment Act				
Adult Employment	857.0	850.0	712.0	987.9
Pilots, Demonstrations, Research	246.0	48.5	25.0	246.0
Youth Activities	942.0	924.0	891.0	1,093.4
OneStop Career Centers	82.0	52.1	49.0	100.0
Dislocated Worker Activities	1,292.0	1,169.0	1,223.0	1,600.0
Office of Disability Employment Policy	28.0	27.0	12.0	47.5
Community College Initiative	124.0	123.0	125.0	150.0
Work Incentives Grants	23.0	14.0	0	28.0
Older Adult Community Service Employment	483.6	521.6	350.0	572.0
VETS Program	223.0	201.0	206.0	233.0
DEP. OF HEALTH AND HUMAN SERVICES				
Health Resources and Services Administration				
Maternal & Child Health Block Grant	693.0	666.0	666.0	850.0
TBI State Grants	9.0	9.0	0	15.0
TBI Protection & Advocacy Grants	3.0	2.9	0	6.0
Universal Newborn Hearing Screening	10.0	12.0	0	12.0
Combating Autism Act	NA	16.5	18.0	18.0
Administration for Children and Families				
Developmental Disabilities Act Programs				
Basic State Grants – Councils on DD	71.0	72.5	72.5	80.0
Protection & Advocacy Systems -- DD	38.0	39.0	39.0	45.0
University Centers for Excellence in DD	33.0	36.9	37.0	41.0
Family Support	5.2	7.2	7.2	17.0
Other Projects of National Significance	6.3	7.0	7.0	7.0
Grants to States to Remove Barriers to Voting	10.9	12.2	12.2	25.0
Protection & Advocacy for Voting Access	4.8	5.3	5.3	10.0
Child Abuse Prevention and Treatment Act	95.0	95.0	106.0	201.0
Head Start	6,786.0	6,902.0	7,027.0	7,971.0
Child Care & Development Block Grant	2,062.0	2,062.0	2,062.0	2,936.0
Centers for Disease Control and Prevention				
Birth Defects, Developmental Disabilities, & Health	124.5	127.3	126.7	144.4
Chronic Disease Prevention	834.0	834.0	834.0	917.4
Environmental Health	149.0	149.0	149.0	153.0
Preventive Health Block Grant	99.0	97.0	0	110.0
Injury Prevention and Control	138.0	138.0	138.0	142.8
Epilepsy Program	7.7	7.7	7.7	9.0
TBI Registries and Surveillance	5.3	5.3	5.3	9.0
Combating Autism Act	-	37.0	42.0	42.0
National Institutes of Health	28,809.0	28,942.0	29,376.0	31,100.0
Natl. Institute of Child Health and Hum. Dev.	1,257.0	1,254.7	1,255.7	1,341.0
Natl. Institute on Deafness & Other Communication Disorders	393.0	394.0	395.0	412.7
Natl. Inst. of Neurological Disorders & Stroke	1,533.0	1,544.0	1,545.0	1,611.5

Natl. Institute on Mental Health	1,402.0	1,405.0	1,407.0	1,498.6
Natl. Institute on Drug Abuse	1,000.3	1,000.7	1,002.0	1,067.7
Natl. Institute on Alcohol Abuse	436.3	436.3	437.0	465.5
Combating Autism Act	-	114.5	129.0	129.0
National Children's Study	69.0	113.0	0	192.0
Lifespan Respite Care Act	NA	0	0	53.3
Social Services Block Grant	1,700.0	1,700.0	1,200.0	1,700.0
Nat'l Family Caregiver Support Program	156.0	153.0	153.0	250.0
SAMHSA				
Children's Mental Health Services	104.0	102.0	114.0	117.3
PATH Homeless Program	54.0	53.0	60.0	61.1
Protection & Advocacy for Indivs. with MI	34.0	35.0	35.0	40.0
Mental Health Block Grant	428.3	421.0	421.0	482.9
Projects of Regional and Nat'l Significance	263.0	299.0	155.0	343.3
DEPARTMENT OF EDUCATION				
Individuals with Disabilities Education Act				
State and Local Grants Part B	10,783.0	10,947.5	11,284.5	12,560.0
Preschool Grants	380.8	374.1	374.1	944.0
Early Intervention Part C	436.4	435.7	435.7	770.0
Part D National Programs				
State Personnel Development	50.1	22.6	48.0	159.5
Technical Assistance and Dissemination	48.9	48.9	48.9	159.5
Personnel Preparation	89.7	88.2	88.0	180.0
Parent Information Centers	25.7	26.5	26.5	95.7
Technology and Media	38.4	39.3	30.9	106.0
Transition Initiative	0	0	2.0	5.5
Research in Special Education (Inst. Ed. Sciences)	71.8	70.6	70.6	244.6
Rehabilitation Services Administration				
Rehabilitation State Grant	2,837.0	2,874.0	2,874.0	3,120.0
Client Assistance Programs	11.7	11.6	11.6	16.0
Rehabilitation Training	38.4	37.8	38.0	42.7
Demonstration and Training Programs	6.5	9.0	9.0	28.1
Recreational Programs	2.4	2.4	0	3.0
Protection & Advocacy for Individual Rights	16.5	16.2	16.2	22.0
Projects with Industry	19.5	19.1	0	50.0
Supported Employment State Grant	29.7	29.2	0	50.0
Migrant & Seasonal Farm workers	2.0	2.0	0	2.3
Independent Living State Grant	22.6	22.2	22.0	25.0
Centers for Independent Living	74.6	73.3	73.0	82.9
Independent Living Serv. for Older Blind Ind.	32.8	32.3	32.0	36.5
State Assistive Technology Programs and TA	30.4	29.9	25.0	32.3
Protection & Advocacy for Assistive Tech.	4.34	4.3	0	6.0
Program Improvements	1.0	1.0	1.0	1.0
Evaluation	1.0	1.0	1.0	1.0
National Institute for Disability & Rehabilitation Research	106.7	105.7	105.7	120.0
Higher Education Act				
Demonstration Projects-Disability (Higher Ed.)	6.8	6.7	0	10.0
Intellectual Disabilities Model Programs*	-	-	-	10.0
Coordinating Center Intellectual Disabilities*	-	-	-	1.5
National Postsecondary Center on Disabilities*	-	-	-	3.0
Instructional Materials Model Programs*	-	-	-	5.0
Teach to Reach Grants*	-	-	-	10.0

Helen Keller National Center	9.0	8.0	8.0	11.7
National Council on Disability	3.1	3.1	2.8	3.7
American Printing House for the Blind	18.0	22.0	22.0	22.0
SOCIAL SECURITY ADMINISTRATION				
Limitation on Administrative Expenses	9,298.0	9,745.0	10,327.0	11,000.0
Protection and Advocacy for S.S. Beneficiaries	7.0	7.0	7.0	10
HOUSING AND URBAN DEVELOPMENT				
Section 811 Supportive Housing for Persons with Disabilities	237.0	237.0	160.0	237.0
McKinney-Vento Homeless Assistance Act	1,327.0	1,315.0	1,729.0	2,000.0
Vouchers Targeted to Nonelderly People with Disabilities	0	30.0	0	50.0
DEPARTMENT OF VETERANS AFFAIRS				
Veterans Health Administration				
Medical Services	25,000.5	29,000.1	34,000.0	34,600.0
Medical Administration	3,100.0	3,500.0	**	3,600.00
Medical Facilities	3,500.0	4,100.0	4,600.0	4,600.0
Research	414.0	480.0	442.0	555.0
VA Administration				
Benefits Administration	1,100.0	1,300.0	1,400.0	1,700.0
General Administration	312.0	278.0	328.0	292.0
DEPARTMENT OF TRANSPORTATION				
5310 Program	117.0	127.0	133.5	133.5
New Freedom Program	81.0	87.5	92.5	92.5
Project ACTION	3.0	3.0	NA	3.0

* Pending Reauthorization of the Higher Education Act

** The FY09 administration request consolidates Medical Services and Medical Administration into one account.

CCD Fiscal Year 2009 Appropriations Recommendations for Selected Federal Programs of Importance to Individuals with Disabilities

Note: The CCD-recommended funding level follows the title of each program.

DEPARTMENT OF LABOR (DOL)

Workforce Investment Act

Adult Employment – \$987.9 million – These grants provide financial assistance to states and territories to design and operate training and employment assistance programs for adults. This is a major funding source for the One-Stop Centers. The President’s budget request proposes a 17 percent cut to this primary job training program. It is already difficult for people with disabilities to receive services from the One-Stop system and reducing resources will only exacerbate the problem.

Pilots, Demonstration, Research – \$246 million – These nationally administered programs serve segments of the population that have special disadvantages in the labor market or serve other national interests. In the past, programs geared to serving people with disabilities were funded through this category.

Youth Activities – \$1.1 billion – These grants support a wide range of activities and services to prepare low-income youth for academic and employment success, including summer employment.

One-Stop Career Centers - \$100 million – There is currently funding of \$74 million to help pay the administrative costs of the One-Stop Centers. The President’s budget would cut that by almost \$20 million to \$56 million. The additional funding is badly needed to help keep states and local governments from having to use service dollars for administrative costs.

Dislocated Worker Program – \$1.6 billion - This is the largest component of the funding sources for the One-Stop system yet the Administration’s budget request once again makes substantial cuts to the program. If individuals with disabilities are to get services through these DOL programs they need to be adequately funded. CCD recommends an increase consistent with other funding for the One-Stop Centers.

Office of Disability Employment Policy – \$47.5 million – This Office provides leadership to eliminate employment barriers to people with disabilities. It works within DOL and in collaboration with other Federal agencies to develop and implement research and pilot projects that examine specific areas of policy inquiry in employment, training, retraining, retention, and employment support services. The President’s budget would cut this program to \$12 million.

Community College Initiative/Community Based Job Training – \$150 million - This is a competitive grant program for building training capacity and training workers through community and technical colleges. CCD supports increased funding for this program but urges DOL to make sure persons with disabilities are adequately included in this program and that the college programs are physically and programmatically accessible.

Work Incentives Grants – \$28 million – These funds provide competitive grants to improve access to and coordination of information, benefits, and services to enable individuals with disabilities to return to work. The disability program navigator positions at One-Stop Centers are funded by this program. The Administration’s budget request argues that these programs should be funded by state and local workforce programs. CCD believes these grants are vital to making One-Stop services available to persons with disabilities.

Older Adult Community Service Employment Program (SCSEP) -- \$572.0 million -- SCSEP is a community service and work based training program for older workers. Authorized by Congress in Title V of the Older Americans Act of 1965, the program provides subsidized, part-time, community service work based training for low-income persons age 55 or older who have poor employment prospects. Persons with disabilities are often in this program or benefit from the services of these older workers.

Veterans' Employment and Training Services (VETS) Program -- \$233 million -- VETS furnishes employment and training services to military service members and veterans through a variety of programs such as the Jobs for Veterans State Grants Programs that fund disabled veterans' outreach and local veterans' employment representatives; Homeless Veterans Reintegration Program; and the Veterans' Workforce Investment Program offering competitive grants for training and retraining veterans in high-skill and high-demand occupations. These programs are vital to assist America’s fighting forces injured in war to return to productive lives. The President's FY 2009 budget recommended a funding level for these programs of \$206 million, a slight increase over the FY 2008 funding level of \$201 million.

DEPARTMENT OF HEALTH AND HUMAN SERVICES (DHHS)

Health Resources and Services Administration (HRSA)

Within DHHS, The Health Resources and Services Administration (HRSA) provides national leadership, program resources, and services to improve access to competent, quality health care which may prevent diminished health that can lead to disability. The programs in the agency, including the Maternal and Child Health Bureau (MCHB), address access to needed health care for vulnerable populations including people with disabilities and chronic health conditions. Health care issues of infants and children are addressed through HRSA. Issues related to clinical preventive services are addressed through programs such as the “Universal Newborn Hearing Screening” and the Special Projects of Regional and National Significance (SPRANS) part of the MCH Block Grant are important programs for training health care professionals to serve people with disabilities and special health care needs and to address issues like rural health care and access to specialists. In addition, public health programs for injury prevention are important public health issues.

Maternal and Child Health Block Grant – \$850.0 million – The Maternal and Child Health Block Grant (MCHB) exists to improve the health of all mothers and children based on health status goals and national health objectives established by the DHHS. It also addresses access to needed health care of vulnerable populations including people with disabilities and chronic health conditions. The program has operated as a federal-state partnership since the Social Security Act was passed in 1935 and Title V initiated support of state efforts to extend and improve health and welfare services for mothers and children. Later it expanded to include other vulnerable populations.

Traumatic Brain Injury (TBI) State Grants -- \$15.0 million – Nationally there are 1.4 million brain injuries per year, with an estimated societal cost of more than \$60 billion per year, including direct care and lost productivity. Research indicates that 50,000 individuals die as a result of Traumatic Brain Injury each year in the United States and an additional 80,000 survive with residual long-term impairments. Today more than 5.3 million Americans are living with a TBI-related disability. TBI can strike anyone at any time – from falls, vehicle crashes, sports injuries, violence, and other causes. The Traumatic Brain Injury Act, originally passed in 1996 and reauthorized in 2000 (**AND IN 2007?**), is designed to promote sound and coordinated public policy in brain injury prevention, research, education, treatment, and community-based services and supports for individuals with TBI and their families. Among various activities authorized under the Act, HRSA makes grants to states to coordinate, expand and enhance service delivery systems in order to improve access to services and supports for persons with TBI and their families. Such services include work re-entry, school transitioning, consumer and professional training, interagency and private sector collaboration, as well as measuring program outcomes. Despite increasing numbers of soldiers returning from war with head injuries, increasing numbers of children being identified as disabled due to head injuries, and the release of an Institute of Medicine (IOM) Report stating the importance of the program to brain injury survivors and their families, the Administration’s FY 2009 budget eliminates the TBI State Grant program. The CCD recommends that Traumatic Brain Injury State Grants be funded at \$15 million.

Protection and Advocacy for Traumatic Brain Injury (PATBI) Program – \$6.0 million – The Traumatic Brain Injury (TBI) Act was re-authorized as part of the Children’s Health Act of 2000 (P.L.106-310) (**AND IN 2007?**),. As part of the TBI Act, Congress created a protection and advocacy program for individuals with brain injuries. This allowed every state to have a TBI Protection and Advocacy program (PATBI) funded at a minimum of \$50,000 per state. In FY 2005, Congress funded the program at \$3.0 million. With this minimal funding, the PATBI program provided protection and advocacy services, information and referral services, and training to more than 50,000 individuals. A review of the program by the Institute of Medicine (IOM) found that, although the program was too new to assess its impact, it has placed a much-needed focus on TBI in the protection and advocacy system, and is part of a larger program that is of vital importance to individuals with brain injuries and their families.

The President’s FY 2006, 2007 and 2008 budgets recommended eliminating the PATBI program. Both House and Senate Appropriations Committees restored this important funding. However, PATBI was funded at the FY 2005 level of \$3 million and then faced an across-the-board cut -- leaving only \$2.97 million to address an ever growing need. The cuts were particularly difficult given the rise in head injuries at home and in Iraq. Once again, in his FY 2009 Budget Proposal, the President calls for zeroing out funding for this critical program. The Administration’s proposal would make it impossible to address the needs of returning soldiers who are facing life-altering challenges because of TBI. The CCD recommends a funding increase of \$3 million for a total FY 2009 appropriation of \$6 million.

Universal Newborn Hearing Screening -- \$12.0 million -- In April of 2000, HRSA awarded the first state Universal Newborn Hearing Screening grants. Approximately 1-3 infants per thousand are born with significant hearing loss. Technology is currently available to conduct cost-efficient, physiological screening on a universal basis prior to hospital discharge. In 1993, less than 5 percent of all infants were screened for hearing loss prior to hospital discharge. Today

the percentage is more than 65 percent and increasing rapidly. Most established programs are able to screen more than 95 percent of all newborns prior to discharge. Typically, 1-3 percent of those screened require referral for diagnostic evaluation. There is clear evidence that the implementation of universal newborn hearing screening substantially lowers the age at which children with congenital permanent hearing loss are identified. Children who are identified early and receive intensive early intervention perform as much as 20-40 percentile points higher than children who do not receive such intervention on school related measures (reading, arithmetic, vocabulary, articulation, percent of the child's communication understood by non-family members, social adjustment and behavior) than children who do not receive such intervention.

Combating Autism Act (HRSA) -- \$42 million -- Late in 2006, President Bush signed into law the Combating Autism Act of 2006 (PL 109-416). The Act authorizes \$189 million for autism spectrum disorders (ASD) and other developmental disabilities in FY 2009 for expanded research, screening, intervention and education through the National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration. Under HRSA, the Act authorizes \$42 million in FY 09 to increase awareness, reduce barriers to screening and diagnosis, promote evidence-based interventions for individuals with autism, and train professionals to utilize valid and reliable screening tools to diagnose autism and provide evidence-based interventions for children with autism and other developmental disabilities. As part of the \$42 million authorized under this section, CCD recommends an appropriation of \$26,200,000, an increase of \$2,000,000 for the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program. This additional funding will enhance the capacity of the national network of LEND programs to train professionals in the interdisciplinary care and treatment of children with autism spectrum disorder and related neurodevelopmental disabilities as well as provide funds to develop up to 4 new LEND programs in states that do not have one.

Administration on Children and Families

Developmental Disabilities Act

The Developmental Disabilities Assistance and Bill of Rights Act (P.L. 106-402) programs focus on the needs of the estimated 4.5 million individuals with developmental disabilities. Developmental disabilities (DD) are severe, life-long disabilities attributable to mental and/or physical impairments, manifested before age 22, that result in substantial limitations in three or more areas of major life activities.

Basic State Grants – Councils on DD – \$80 million – For more than thirty years, Councils have played a critical role at the State and Federal level in helping States and Territories develop, improve and expand the system of services and supports for people with developmental disabilities. Councils work to ensure that these individuals participate fully in their communities through full integration and inclusion in the economic, political, social, cultural, religious and educational mainstream of our nation. DD Councils strive to improve the quality of supports and services for these individuals in a more family friendly manner, regardless of where they choose to live. It is imperative that Congress appropriate adequate funding to State and Territorial Councils on Developmental Disabilities in FY 2009. CCD is asking Congress to appropriate \$80 million for this important program.

Protection and Advocacy Program for Individuals with Developmental Disabilities (PADD) – \$45.0 million – The Protection and Advocacy Program for Individuals with Developmental Disabilities (PADD) was the first P&A program authorized by Congress, as part of the Developmental Disabilities Assistance and Bill of Rights Act in 1975. As disability policy has moved away from institutions to the community, PADD advocacy has played a major role in the de-institutionalization movement. However, tens of thousand of individuals with developmental disabilities continue to reside in state-operated or privately-owned congregate residential facilities, among them, 1,600 children under the age of 21.

Researchers in the field of developmental disabilities recently reported there has been a slowing of the trend toward deinstitutionalization. Since the PADD program has been an extremely effective tool in the move to the community (which the President continues to call for in his New Freedom Initiative), increased PADD funding could help stem this tide. Unfortunately, in his FY 2009 budget proposal, President Bush once again proposes level funding for the PADD program. In reality, this is a cut and will lead to the PADD program being less able to respond to the critical needs of people with developmental disabilities.

University Centers for Excellence in DD (UCEDDs) – \$41 million – CCD recommends \$41 million for University Centers for Excellence in Developmental Disabilities (UCEDDs) which would allow up to four capacity-building grants of \$250,000 to enable up to four UCEDDs to work in partnership with collaborating Minority Serving Institutions (as defined in the Higher Education Act) to focus on research, health, education, and services for African Americans, Hispanic Americans, Native Americans, Pacific Islanders, Asian Americans, and other ethnically and culturally diverse populations. The increase would also help UCEDDs address critical, emerging national needs, such as the growing number of individuals with Autism Spectrum Disorders and related neurodevelopmental disorders; allow the Administration on Developmental Disabilities to expand National Training Initiative grants; and provide for a cost-of-living increase to the Centers.

The DD Act requires UCEDDs to promote opportunities for individuals with developmental disabilities to exercise self-determination, be independent, productive and integrated and included in all facets of community life. The network of UCEDDs accomplishes this by providing direct services and supports to people with developmental disabilities, their families, and communities. This includes state-of-the-art diagnosis, evaluation, support services for children and adults in health care, cognitive development, behavior disorders, education, daily living, and work skills.

Family Support – \$17.0 million – The Family Support Program promotes a comprehensive state system of family support services for families of children with disabilities so that families can stay together and individuals can live in the community. The Family Support program, which has been included in the PNS program since 1999, should have its own appropriations line item due to the high need and ongoing significance of Family Support services to families throughout the nation.

Other Projects of National Significance (PNS) – \$7.0 million – Projects of National Significance address particular national needs, such as Education, Housing, Medicaid, and Transportation.

Grants to States to Remove Barriers to Voting – \$25.0 million – The accessibility grant funds under the Help America Vote Act of 2002 (HAVA) provide states with assistance to make federal elections accessible to citizens with disabilities. These funds may be used by states and units of local government to make polling places accessible, provide individuals with disabilities information and outreach regarding the accessibility of the voting process, and train election officials, poll workers and election volunteers on how to best promote the access and participation of individuals with disabilities in elections. For the last five fiscal years grants appropriated to states under HAVA have been inadequate to counteract decades of inaccessibility which have led to the entrenched disenfranchisement of individuals with disabilities. The CCD recommends funding of the grant program to \$25 million to ensure that individuals with disabilities can participate in the democratic process.

Protection and Advocacy for Voting Access (PAVA) – \$10.0 million – The goal of the Help America Vote Act of 2002 (HAVA) was to make major improvements in voting systems across the country. As part of HAVA, Congress acknowledged the unique obstacles faced by people with disabilities and authorized funding for the Protection and Advocacy for Voting Access program. Individuals with disabilities have faced innumerable problems as they attempt to exercise their right to vote. These problems include the inaccessibility of many polling places to people with physical disabilities; the lack of private and independent voting for many individuals with a variety of disabilities; the failure to provide voting and registration materials in accessible formats to people with sensory disabilities; and the outright denial of the right to register and vote based on false assumptions about the competence of people with cognitive or psychiatric disabilities. The unique role of PAVA programs under HAVA provides them the opportunity to assist voters with disabilities trying to exercise their right to vote, as well as lend their expertise to election officials who are trying to comply with HAVA and other statutes relating to individuals with disabilities. The PAVA program is administered through the Department of Health and Human Services, Administration on Developmental Disabilities. The President's FY 2009 budget recommended level funding of \$5.3 million for this program. In reality, level funding is a cut that will have a negative impact on the program's ability to do its job of ensuring the enfranchisement of people with disabilities. The CCD recommends a total FY 2009 appropriation of \$10 million.

Child Abuse Prevention and Treatment Act – \$201 million – HHS reports 905,000 children abused and neglected in the U.S. in 2006. Without adequate family support, children with disabilities, are almost four times more likely to be victims of neglect, be physically abused, experience emotional abuse, or be sexually assaulted than children without disabilities. In addition, child maltreatment has been shown to be a significant cause of serious disability in children. Other studies have shown that significant proportions of children in foster care may have serious health and developmental problems. In particular, we must ensure that funding is dedicated to community-based child abuse and neglect prevention activities, such as respite, that can keep families out of protective services systems and avoid more costly foster care.

CCD recommends funding the Child Abuse Prevention and Treatment Act (CAPTA) programs at \$201 million in the FY09 broken out by programs as follows:

- CAPTA basic state grants at \$84 million for strengthening states' child protection systems,
- CAPTA Title II community-based prevention grants funding at \$80 million, and
- CAPTA discretionary research and demonstration grants at \$37 million.

Head Start – \$7.971 billion – More than 132,000 preschool children with disabilities receive their special education services at a Head Start Program. This comprehensive early education and care program supports more than 1,054,700 low income children and their families. It is a critical partner to the Individuals with Disabilities Education Act in helping young children with disabilities enter school ready to learn.

Child Care & Development Block Grant (CCDBG) – \$2.6 billion – At its current rate of funding, the Child Care and Development Block Grants serves one out of every seven eligible children. Forty-five percent of mothers with an infant with a disability do not return to work because they cannot find appropriate child care. CCDBG funds are the only federal source of support for child care tuition for low income children, including children with disabilities. The block grant also supports essential research and training activities designed to increase the supply of quality, affordable care for children with and without disabilities.

Centers for Disease Control and Prevention (CDC)

The Centers for Disease Control and Prevention (CDC) promotes health and quality of life by prevention and control of injuries, and disability. The CDC addresses issues related to specific physical and mental impairments such as epilepsy and health issues related to toxic environments which can diminish health. Also, the Agency promotes healthy lifestyles that prevent chronic health disorders and life threatening injuries that may be precursors of disability. The CDC programs conduct and support research that develops and presents scientific evidence regarding all aspects of public health.

Birth Defects, Developmental Disabilities and Health – \$144.4 million – The National Center on Birth Defects and Developmental Disabilities (NCBDDD) promotes the health of babies, children, and adults, and enhances the potential for full, productive living. The Center's work includes identifying the causes of birth defects, researching birth defects, helping women to have healthy pregnancies, helping children to develop and reach their full potential, and promoting health and well-being among people of all ages with disabilities.

Chronic Disease Prevention – \$917.4 million – The National Center for Chronic Disease and Prevention and Health Promotion is at the forefront of the nation's effort to prevent and control chronic disease such as heart disease, diabetes, epilepsy, and cancer. The Center conducts studies to better understand the causes of the diseases, supports programs to promote healthy behaviors, and monitors the health of the nation through surveys. Critical to the success of these efforts are partnerships with state health and education agencies, voluntary associations, private organizations, and other federal agencies. Together, the centers and its partners are working to create a healthier nation.

Environmental Health – \$153.0 million – Persons exposed to toxins in the environment may suffer adverse health consequences that could lead to disability. One program associated with environmental health is the Environment Tracking Network which documents links between environmental hazards and chronic diseases that can lead to disability. This program also supports environmental health programs that include prevention of asthma, prevention of childhood lead poisoning, and emergency responses to chemical and radiological exposures. All of these conditions can diminish health and lead to disability.

Preventive Health and Health Services Block Grant – \$110 million – The Preventive Health Services Block Grants provide states with funds for preventive health services. These funds can be used to achieve progress toward the priorities and objectives of the U.S. Public Health program “Healthy People 2010.” These goals include improved behavioral lifestyles such as appropriate physical activity; nutrition; control of substance abuse; prevention of chronic and mental health disorders; and access to clinical preventive services. “Healthy People 2010” identifies areas of public health to prevent diminished health status that can lead to disability. The Preventive Health Block Grant contributes to many objectives of the U. S. Public Health Service Act.

Injury Prevention and Control – \$142.8 million – Estimates are that there are approximately 5 million persons injured each year resulting in 150,000 deaths. Many injuries are permanent and diminish health in a way that eventually can lead to disability. More than 10 percent of all disability is caused by injuries. The risk of injury is so great that most persons sustain a significant injury at sometime during their life. This widespread human damage too often is taken with the erroneous belief that injuries happen by chance. The Center for Disease Control and Prevention indicates that many injuries are not “accidents” or random, most injuries are predictable and preventable. This program in CDC provides state grants for all aspects of injury prevention and control.

Epilepsy Program – \$9 million – The CDC epilepsy program is making valuable progress in research, epidemiology and surveillance, early detection, improved treatment, public education and expansion of interventions to support people with epilepsy and their families and communities. The program is a partnership with the CDC to develop and implement programs based on the recommendations of *Living Well with Epilepsy II*. The program supports activities such as the First Responders Program which trains police, firefighters, and EMTs to recognize and treat seizures, the School Nurse Program which trains thousands of school nurses across the nation in how to recognize and treat students in the school environment with epilepsy, and the Seniors and Seizures program, the latest program addressing the needs of the fastest growing population of people having seizures – often for the first time. The President’s budget for FY 2009 recommends level funding of \$7.6 million. The CCD recommends that the program’s funding be increased to \$8.5 million in order to continue strong research at the CDC for epilepsy and increasing funding for community-based programs that help people with epilepsy to live well in their communities.

Traumatic Brain Injury (TBI) Registries and Surveillance – \$9.0 million – The Centers for Disease Control and Prevention provides funding to help states establish and maintain statewide registries and surveillance systems to determine incidence, cost, causes, contributing factors, and other data necessary for TBI prevention, developing service delivery, and linking individuals with traumatic brain injury and families to services.

Combating Autism Act - \$42 million - Late in 2006, President Bush signed into law the Combating Autism Act of 2006 (PL 109-416). The Act authorizes \$189 million for autism spectrum disorders (ASD) and other developmental disabilities in FY 2009 for expanded research, screening, intervention and education through the National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration. Under the CDC, the Act provides \$18 million in FY 09 for the CDC's Disabilities Surveillance and Research Program. This program supports data collection, analysis, and reporting, so that we can better understand the scope of the autism epidemic. It also supports the establishment of regional centers of excellence to collect and analyze information on the number, incidence, correlates, and causes of autism spectrum disorder and other developmental disabilities.

National Institutes of Health (NIH)

In recent years NIH has been unable to keep pace with the biomedical rate of inflation, and its purchasing power has decreased by more than 13 percent since FY 2003. To ensure that progress in basic, translational and clinical research is sustained, CCD supports an FY 2009 appropriation of \$31.1 billion, an increase of approximately 6.6 percent. The NIH uncovers new knowledge that may ameliorate or prevent diminished health that can lead to disability. The application of this new knowledge can lead to better healthcare for everyone including persons with disabilities. Congress should specifically authorize NIH to use appropriated funds for use for planning activities for and implementation of the National Children's Study. We believe Congress should appropriate sufficient funds for both development and ongoing implementation.

National Institute of Child Health & Human Development (NICHD) – CCD supports an appropriation of \$1.34 billion for NICHD, a 6.6 percent increase over FY 2008. The NICHD, created by Congress in 1962, supports and conducts research on topics related to the health of children, adults, families, and populations. NICHD provides core funding for the national network of Developmental Disabilities Research Centers, the world's largest concentration of scientific expertise in the fields of intellectual and developmental disabilities. During the last few fiscal years critical research being conducted at Intellectual and Developmental Disabilities Research Centers (IDDRCs) has slowed due to cuts in the NIH budget. Recently funded IDDRCs experienced approximately an 11% cut, even though they received outstanding scientific evaluations. To address our concerns, we ask that you increase funding by approximately 6.6% to \$1.34 billion for the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) and restore cuts in IDDRC funding.

National Institute on Deafness & Other Communication Disorders (NIDCD) – \$412.7 million – NIDCD supports scientific discovery to understand both normal processes and those processes that disrupt or devastate human communication systems. NIDCD supports a wide range of research, including the development of augmentative and assistive communication technologies, biomedical imaging, nanotechnology and linguistics. NIDCD supports scientists at all points of their careers, from high school to senior scientists and broadly disseminates research results to the public and to medical and health professionals.

National Institute of Neurological Disorders and Stroke (NINDS) – \$1.6 billion – More than 600 disorders affect the nervous system. Common disorders such as stroke, epilepsy, Parkinson’s disease, and autism are well-known. Many other neurological disorders are rare – known only to the affected patients and families, their doctors, and scientists who look to rare disorders for clues to a general understanding of the brain as well as for treatments for specific diseases. Neurological disorders strike an estimated 50 million Americans each year, exacting an incalculable personal toll and an annual economic cost of hundreds of billions of dollars in medical expenses and lost productivity. NINDS conducts and supports research on brain and nervous system disorders.

National Institute of Mental Health (NIMH) – \$1.5 billion – The National Institute of Mental Health is the leading federal agency supporting basic biomedical and behavioral research related to mental illness. An overwhelming body of scientific research demonstrates that: (1) mental illnesses are diseases with clear biological and social components; (2) treatment is effective; and (3) the nation has realized immense dividends from five decades of investment in research focused on mental illness and mental health.

National Institute on Drug Abuse (NIDA) – \$1.1 billion – An estimated 23 million Americans struggle with serious substance abuse problems for which treatment is needed. Drug abuse leads to lost productivity, transmission of communicable diseases, domestic violence, drug abuse, and diminished health that can lead to disability. Drug abuse is up among American teenagers and there has been increased use, abuse and dependence on methamphetamine (1.4 million Americans had used the drug in the year 2004). Effective research is need in the area of drug abuse to prevent diminished health that can lead to disability.

National Institute on Alcohol Abuse and Alcoholism (NIAA) – \$465.5 million – Alcohol abuse is up among young Americans. Addiction to alcohol can have a devastating impact on individuals and their families, which may diminish health and lead to disability. Thus, there is need for research for prevention and treatments of alcohol addiction. One needed area of alcohol research is its co-occurrence with drug abuse and mental illness. The CDC indicates that 28 percent to 30 percent of Americans have an alcohol substance abuse and/or mental health problems and one in three adults have co-occurring disorders, which complicate treatments. Therefore, funding of the NIAAA is an important research initiative to understand the complexities for prevention and treatments associated with drug abuse.

Combating Autism Act (NIH)-- \$129 million - Late in 2006, President Bush signed into law the Combating Autism Act of 2006 (PL 109-416). The Act authorizes \$189 million for autism spectrum disorders (ASD) and other developmental disabilities in FY 2009 for expanded research, screening, intervention and education through the National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration. Under NIH, the Act provides \$129 million to expand, intensify, and coordinate the activities of the National Institutes of Health with respect to research on autism spectrum disorder. This includes funding for research into the causes of autism, diagnosis, early detection, prevention, services, supports, intervention, and treatment of autism spectrum disorder.

National Children’s Study -- \$192.0 million -- After 6 years of planning, centers would be established to collect genetic material and blood samples and to record children’s exposure to everything from pesticides to air pollution, as well as the physical and social environment, to

determine how these factors affect the onset of disease. Doctors and scientists hope this project will establish links to recent increases in childhood cancers, asthma, autism, diabetes and a wide range of diseases.

Lifespan Respite Care Act -- \$53.3 million -- Lifespan Respite is a coordinated system of accessible, community-based respite care services for caregivers and individuals regardless of age or special need. Respite care is planned or emergency short-term relief to caregivers from the demands of ongoing care for an individual with special needs. *The Lifespan Respite Care Act* authorizes competitive grants to Aging and Disability Resource Centers in collaboration with a public or private non-profit state respite coalition or organization to make quality respite available and accessible to family caregivers regardless of age or disability. The law allows grantees to identify, coordinate and build on federal, state and local respite resources and funding streams, and would help support, expand and streamline planned and emergency respite, provider recruitment and training, and caregiver training. The Lifespan Respite Care Act passed in the 109th Congress. President Bush's FY 2009 budget recommends NO funding for the program. CCD recommends funding at the FY 2009 authorized level of \$53.3 million.

Social Services Block Grant (SSBG) – \$1.7 billion – The Title XX Social Services Block Grant provides a myriad of services and supports for individuals with disabilities in numerous states. Many states use SSBG funding to fill major gaps in their systems that serve vulnerable people. The CCD recommendation is intended to restore Title XX funding no longer available to states since the beginning of this decade.

National Family Caregiver Support Program – \$250.0 million – The enactment of the Older Americans Act Amendments of 2000 (Public Law 106-501) established the National Family Caregiver Support Program (NFCSP). The program serves family caregivers of older adults (age 60 years and older) and individuals of any age with Alzheimer's or similar neurological disorders; and grandparents and relative caregivers age 55 and older of children not more than 18 years of age (including grandparents and relative caregivers who are sole caregivers of children over age 18 who have intellectual or developmental disabilities). The program calls for all states to offer five direct services that best meet the range of caregivers' needs, including:

- Information to caregivers about available services;
- Assistance to caregivers in gaining access to supportive services;
- Individual counseling, organization of support groups, and caregiver training to assist caregivers in making decisions and solving problems relating to their roles;
- Respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities; and
- Supplemental services, on a limited basis, to complement the care provided by caregivers.

Substance Abuse and Mental Health Service Administration (SAMHSA)

The Substance Abuse and Mental Health Service Administration (SAMHSA) builds on resilience and facilitates recovery for people with or at risk of mental illness. These programs advance public health and social services that ameliorate and prevent issues associated with mental health which can lead to disability. The agency provides for programs that address issues of both children and adults. There are provisions for research and demonstration projects that can address mental health issues of regional and

national significance. The Center for Mental Health Services (CMHS) promotes improvements in mental health services that enhance the lives of adults who experience mental illnesses and children with serious emotional disorders; fills unmet and emerging needs; bridges the gap between research and practice; and strengthens data collection to improve quality and enhance accountability.

Children’s Mental Health Services – \$117.3 million – Established in 1993, the Children’s Mental Health Services Program provides six-year cooperative agreements to public entities for developing comprehensive home and community-based mental health services for children with serious emotional disturbances (SED) and their families. The program assists states, political subdivisions of states, American Indian and Alaska Native tribes, territories, and the District of Columbia to implement systems of care that are child-centered, family-driven, and culturally competent. Studies have shown that systems-of-care improve the functioning of children and youth with SED, and significantly reduce unnecessary and expensive hospitalizations.

Community based services provided through these systems-of-care initiatives include: diagnostic and evaluation services; outpatient services provided in a clinic, school or office; emergency services; intensive home-based services; intensive day-treatment; respite care; therapeutic foster care; and services that assist the child in making the transition from children’s services to adult services. Often, services and supports for children with serious emotional disturbance and their families who are involved with more than one child-serving system are uncoordinated and fragmented. Typically, the only options available are outpatient therapy, medication, or hospitalization. Frequently there are long waits for these services because they are operating at capacity, making them inaccessible for new clients, even in crisis situations. The national evaluation data provide evidence that children and youth enrolled in systems-of-care experience noticeable improvements on both emotional and behavioral measures.

PATH Homeless Formula Grant – \$61.1 million – The Projects for Assistance in Transition from Homelessness (PATH) formula grant program is a critical resource for states and localities in reaching people with mental illness who experience chronic homelessness. PATH provides funding to states, localities and non-profits to support individuals who are homeless (or are at risk of homelessness) and have a serious mental illness and/or a co-occurring substance abuse disorder. Federal PATH funds, when combined with state and local matching funds are the only resources available in many communities to support the range of services needed to effectively reach and engage individuals with severe mental illness and co-occurring substance abuse disorders. In addition to the outreach and engagement services funded by PATH, local communities also need assistance in funding ongoing services in permanent supportive housing targeted to individuals exiting chronic homelessness, including permanent housing financed through HUD’s McKinney-Vento Homeless Assistance Act. A focus on ending chronic homelessness is critically important to addressing the enormous economic and social costs associated with individuals who stay homeless for long periods and impose enormous financial burdens on communities as they cycle through hospital emergency rooms, jails, shelters and the streets.

Protection and Advocacy for Individuals with Mental Illness (PAIMI) – \$40.0 million – In 1986, Congress authorized the PAIMI program in the Protection and Advocacy for Individuals with Mental Illness Act. PAIMI is funded through the SAMHSA. The program originally was established to provide protection and advocacy services to individuals with mental illness, who were or had recently resided in institutional settings. In 2000, Congress greatly expanded the PAIMI mandate to include all individuals with significant mental illness, including people living in the community in all settings. Unfortunately, as the PAIMI mandate has expanded, funding for the program has shrunk. In FY 2005 Congress funded

the PAIMI program at \$34.3 million, a decrease from 2004. Unfortunately, FY 2006 funding was further decreased to \$34 million. In his FY 2007, 2008 and 2009 budget proposals, President Bush again requested \$34 million. Level funding, in reality, is a cut that will limit the ability of PAIMI programs to serve a growing population made larger by recent natural disasters and war injuries. In late 2004, it was reported that 20 percent of returning Iraq veterans seeking VA care have done so for mental health issues. The needs of these returning veterans must be considered as funding decisions are made about the PAIMI program. The CCD recommends a funding increase of \$6.0 million, for a total FY 2009 appropriation of \$40 million.

Mental Health Block Grant – \$482.9 million – The Community Mental Health Services Performance Partnership Block Grant is the principal federal discretionary program supporting community-based mental health services for adults and children services. The Block Grant is a flexible source of funding that is used to support new services and programs, expand or enhance access under existing programs, and leverage additional state and community dollars. The Block Grant is vital because it gives states critical flexibility to: (1) fund services that are tailored to meet the unique needs and priorities of consumers of the public mental health system in that state; (2) hold providers accountable for access and the quality of services provided; and (3) coordinate services and blend funding streams to help finance the broad range of supports, including medical and social services, that individuals with mental illnesses need to live safely and effectively in the community.

Projects of Regional & National Significance – \$343.3 million – The Center for Mental Health Services (CMHS) addresses priority mental health care needs of regional and national significance by developing and applying best practices, providing training and technical assistance, providing targeted capacity expansion, and changing the service delivery system through family, client-oriented and consumer-run activities. CMHS employs a strategic approach to service development. The strategy provides for three broad steps: (1) developing an evidence base about what services and service delivery mechanisms work; (2) promoting community readiness to adopt evidence-based practices; and (3) supporting capacity development.

The Children's Health Act (P.L. 106-310), enacted in October 2000, re-authorized most of CMHS' system-improvement activities, and it authorized new programs, many of which are included in CMHS' Programs of Regional and National Significance. PRNS allow state and local mental health authorities to access information about the most promising methods for improving the performance of programs. The Administration's budget proposal would cut funding for the PRNS by roughly \$35 million or nearly 13 percent. The proposed PRNS budget would cut funding for the Youth Violence Prevention program by almost 20 percent, or \$18 million. PRNS includes the programs in its Knowledge Development and Application Program (KDA), its Targeted Capacity Expansion Program (TCE), as well as a number of other programs.

DEPARTMENT OF EDUCATION

Individuals with Disabilities Education Act (IDEA)

IDEA Part B State Grants – \$12.56 billion – This figure represents the FY 2009 funding level as authorized by the IDEA Amendments of 2004. This appropriation would put this historically underfunded program back on the glide path to fully fund IDEA Part B as promised to states, school systems and parents when the law was originally enacted over 30 years ago.

IDEA Preschool Grants – \$944.0 million – Again, this recommendation represents a substantial increase over the FY 2007 appropriation. Despite the growth in the numbers of children each year served by the preschool program, funding for this program has been stagnant for at least 5 years, was cut in 2005 and 2006 and frozen in 2007. When it was first created in 1986, the federal special education preschool program aspired to provide \$1500 per child. At the current funding level, states receive only about \$500 to provide a free, appropriate public education for preschoolers with disabilities.

IDEA Part C Early Intervention – \$770.0 million – This recommendation represents a substantial increase over the FY 2008 appropriation due to the new requirements for newborn, infant and toddler screening and evaluations by and referrals to Part C programs as a result of the 2004 reauthorization of CAPTA.

IDEA Part D National Programs

State Personnel Development – \$159.5 million – This amount will assist states in meeting the acute special education teacher and related personnel shortages in practically every state and help school systems obtain and retain special education personnel that meet the new "highly qualified" standards in No Child Left Behind.

Technical Assistance and Dissemination – \$159.5 million – This increase will spur the additional activity necessary to better implement the 2004 Amendments to IDEA and the No Child Left Behind provisions related to students with disabilities, in particular the new so-called 1 percent and 2 percent rules on assessments.

Personnel Preparation – \$180.0 million – The rationale for this increase is essentially the same as for State Personnel Development. The special education manpower needs are immense. There are tens of thousands of unqualified teachers working in special education classes today

Parent Information Centers – \$95.7 million – These Centers have the important role of informing and training parents of special education students about the new IDEA Amendments and the final regulations to implement those amendments which are due to be released later this year.

Technology and Media – \$106 million – CCD requests a small increase for these programs, not a cut as requested by the Bush Administration.

Transition Initiative – \$5.5 million – Transition is one of the most critical activities in special education. These services help prepare students in advance for post-high school life, whether they wish to go to college, get a job, or undertake vocational training.

Research in Special Education (Institute on Educational Sciences -- IES) -- \$244.6 million – The federal research and innovation agenda in special education was recently turned over to the new IES. It is vital that research and innovation in special education keep pace with the challenges of the 2004 Amendments to IDEA, the NCLB and new methods to identify and educate students with all types of disabilities.

Rehabilitation Services Administration (RSA)

Vocational Rehabilitation (VR) State Grants – \$3.1 billion – The increase recommended by CCD would enable the vocational rehabilitation system to serve more individuals with disabilities and to provide the range of services needed by individuals with the most significant disabilities. This program is not simply another employment training program. It provides assessments, pre-vocational training, assistive technology, job placement consistent with the strengths and abilities of individuals with disabilities, and follow-along services to assist in job retention.

Client Assistance Program (CAP) – \$16.0 million – The Client Assistance Program (CAP) was established so that the rights of individuals with disabilities who are clients of the vocational rehabilitation (VR) system are protected. Given the focus of the President's New Freedom Initiative on community living, the CAP role continues to expand as the programs attempt to assist more individuals with disabilities to negotiate changing employment and training systems. More than 60 percent of individuals with disabilities are unemployed. This extremely high unemployment rate harms not only people with disabilities, but also the overall economic and fiscal health of the nation. Level funding – combined with across-the-board cuts to domestic programs – has had a detrimental effect on CAP's ability to serve all those who need services over the past few fiscal years. Unfortunately, the President's FY 2009 budget proposal funds CAP at its FY 2006, 2007 and 2008 level. Level funding is – for all intents and purposes – a cut because the program is not able to keep up with growing costs. This will lead to a cut in services as more and more people with disabilities seek employment. CCD recommends a total FY 2009 appropriation of \$16 million.

Rehabilitation Training – \$42.7 million – This program makes grants to state units and other public and nonprofit entities, including institutions of higher learning, to help ensure that adequate skilled personnel are available to provide rehabilitation services to persons with disabilities. Chronic under-funding of this program has caused agencies to deal with staffing shortages which have translated into case loads far higher than appropriate for the individualized training needed by persons with disabilities.

Special Demonstration and Training Programs – \$28.1 million – This program awards competitive grants to community rehabilitation programs, designated state units, and other public and nonprofit entities for the development of innovative programs to help individuals with disabilities achieve vocational outcomes. Continued changes in configuration of jobs make it necessary to invest in the development of new methods and resources to achieve vocational outcomes.

Recreation Programs – \$3.0 million – These small grants are to provide individuals with disabilities with recreational activities and related experiences to aid in their mobility, socialization, independence, and community integration.

Protection and Advocacy of Individuals Rights (PAIR) – \$22.0 million – The Protection and Advocacy of Individuals Rights (PAIR) program is authorized as part of the Rehabilitation Act. The PAIR program was developed to help protect the rights of all those people with disabilities who are ineligible for the two basic protection and advocacy programs – those for children and adults with developmental disabilities (PADD) and for individuals with mental illness (PAIMI).

More people with disabilities are eligible for PAIR than any other federal protection and advocacy program.

PAIR-eligible individuals include those with physical disabilities, such as spinal cord injury and amputations; sensory disabilities, such as blindness and deafness; and neurological impairments, such as multiple sclerosis and muscular dystrophy. The population of these individuals is growing because of advances in health care. In addition, many of the 16,420 soldiers who have been wounded so far in the conflict in the Middle East -- many of whom now have multiple disabilities -- also are eligible for PAIR advocacy assistance. Congress funded PAIR in 2005 at \$16.6 million—less than the previous year’s funding because of an across-the-board cut. In 2006, a Presidential recommendation of level funding, accompanied by Congressional across-the-board cuts, resulted in another cut to the PAIR program leaving only \$16.489 million. In his FY 2009 Budget Proposal, President Bush once again proposed level funding for this program. Level funding, in reality, is a cut and will limit the efforts of PAIR to address the needs of individuals with a wide range of disabilities, including the many soldiers returning with a wide range of physical disabilities. The CCD recommends a funding increase of \$5.52 million, for a total FY 2009 appropriation of \$22 million.

Projects with Industry (PWI) – \$50.0 million – The purpose of the PWI program is to create and expand job and career opportunities for individuals with disabilities in the competitive labor market by engaging talent and leadership of private industry as partners in the rehabilitation process. Under the PWI program, grants are provided on a competitive basis to employers and profit making and non-profit organizations. Successive Presidential budget requests have recommended zero funding based on the assumption that these programs would be integrated into Rehabilitation Act programs. However, no funding increase has been proposed in the basic rehabilitation program. Additional funding is needed to insure that all states and major population areas have PWI’s available to help place people with significant disabilities into competitive community jobs.

Supported Employment State Grant – \$50.0 million – This program makes formula grants to assist states in developing collaborative programs with appropriate public and private nonprofit agencies to offer supported employment services for individuals with disabilities. Successive Presidential budget requests have provided zero funding for the program with the justification that the basic state grant program can provide supported employment services. Unfortunately, these same budgets have recommended no increase in the basic state grant program to cover integration of these programs.

Migrant and Seasonal Farm Workers – \$2.3 million – This funds a number of projects that work specifically with migrant and seasonal farm workers with disabilities to provide them with vocational rehabilitation services. While very small, this program meets a need that is unlikely to be addressed by the larger programs.

Independent Living – State Grants – \$25.0 million
Centers for Independent Living – \$82.9 million;
Services for Older Blind Individuals – \$36.5 million

Independent Living State Grants, Centers for Independent Living, and Services for Older Blind Individuals provide a wide variety of services to assist individuals, often those who have recently

encountered a disabling condition, that are not available through any other single source. This is particularly true for the Independent Living and Services for Older Blind Individuals program. Program service requirements have increased over time, and new initiatives for community living make it even more important that increased resources be devoted to this program

State Assistive Technology Programs and Technical Assistance -- \$32.3. million – The Assistive Technology Act of 1998, as amended, was reauthorized, unanimously endorsed by the House and the Senate, and signed into law by President Bush in October 2004. Programs funded under the Act have had a significant impact on the lives of people with disabilities who depend on assistive technology. The 2004 amendments to the AT Act constitute the third major programmatic change in the AT Programs since its inception in 1988. Every state and US territory receives funding under the AT Act to provide services to people with disabilities and other targeted individuals including family members, guardians, employers, educators, therapists, policy-makers, and health care providers. Under the reauthorized law, state programs are responsible for providing more services that bring assistive technology directly into the hands of those who need it. State programs are now required to provide state financing activities, device loan, device demonstration and device reutilization services in addition to previously required activities including information and referral, technical assistance, training and coordination and collaboration. As a result of the state AT Programs individuals with disabilities and elderly persons have been able to remain in their homes and avoid institutionalized nursing home care with increased costs; participate fully in their educational programs; acquire and/or keep jobs; establish businesses; and participate in community activities. The programs are also a resource for assistive technology solutions for veterans returning from Iraq with injuries and needs they never anticipated. The required activities for states require additional funds. Unfortunately, increased requirements were not met with increased resources.

Protection and Advocacy for Assistive Technology (PAAT) Program – \$6.0 million – The Assistive Technology Act of 1998, as amended, also authorizes the Protection and Advocacy for Assistive Technology program (PAAT). The PAAT program is funded through the Department of Education, Rehabilitation Services Administration. PAAT has been a major force in ensuring that children and adults with disabilities can get access to critically needed assistive technology in a variety of settings – school, home, and at work. Unfortunately, in his FY 2007, 2008 and 2009 budget proposals, President Bush again proposed eliminating the PAAT program despite its role in providing information, assistance, and training to thousands of individuals with disabilities. Policymakers promoting the use of health information technologies should not forget the very real effect that assistive technology can have on the quality of life experienced by individuals with disabilities – from the basic act of communicating to the use of assistive devices for complex work activities.

Program Improvement – 1.0 million -- Funds are used to promote broad-based planning and coordination, improve accountability, and enhance the Department's ability to address critical areas of national significance in achieving the goals of the Rehabilitation Act. Examples of program improvement activities include technical assistance, dissemination, and performance measurement activities.

Evaluation – 1.0 million -- Studies are conducted to evaluate the impact and effectiveness of various programs authorized under the Rehabilitation Act.

National Institute on Disability and Rehabilitation Research -- \$120.0 million – This institute carries out a comprehensive program of rehabilitation research. Through grants and contracts, it supports the conduct and dissemination of research aimed at improving the lives of people with disabilities. The development and utilization of new technologies in a wide variety of areas makes it necessary to advance funding for application of these technologies to the needs of individuals with disabilities.

Higher Education Act

Demonstration Projects – Disabilities (Higher Ed.) - \$10.0 million – Students with disabilities are far less likely than their non-disabled peers to participate in post-secondary education. This program is the only program in the Higher Education Act that is exclusively dedicated to increasing the participation and success of students with disabilities in higher education. Through model demonstrations, technical assistance, and professional development, these grants enhance the effectiveness of administrators, faculty and staff in meeting the needs of students with disabilities in higher education. Though modest, this investment is critical in supporting the educational success of students with disabilities and ensuring their access to higher education.

New Higher Education Programs Pending Reauthorization of the Higher Education Act – Congress is currently in the process of reauthorizing the Higher Education Act. The reauthorization bills currently being considered include several new programs that will expand opportunities for students with disabilities and improve the quality of postsecondary education for these students.. CCD recommends fiscal 2009 funding for all the new initiatives listed in the table on page 11. These include the following:

- Model Comprehensive Transition and Postsecondary Programs for Students with Intellectual Disabilities – \$10 million
- Coordinating Center for Technical Assistance, Evaluation, And Development of Accreditation Standards – \$1.5 million
- National Center for Information and Technical Support for Post-Secondary Students with Disabilities -- \$3 million
- Model Demonstration Programs to Improve Access to Instructional Materials -- \$5 million
- Teach to Reach Program -- \$10 million

Helen Keller National Center – \$11.7 million – The Helen Keller National Center provides services, training, and technical assistance to professional and allied personnel at its national headquarters and at the regional level to improve the provision of direct services to individuals who are deaf and blind. Program funding should be increased to provide services to a population who require intensive levels of service.

National Council on Disability (NCD) – \$3.7 million – The National Council on Disability conducts vital research studies on key disability policy issues. Results of these studies are utilized by Congress and the Administration, as well as by the disability community to advance national disability policy to improve the lives of the more than 54 million children and adults with disabilities in the United States. The CCD fiscal recommendation would restore the NCD to its funding level for 2005, adjusted for inflation.

American Printing House for the Blind – \$22.0 million – In the most recent census taken by the American Printing House for the Blind, 57,983 blind and visually impaired students were registered. APH is requesting a \$20 million appropriation for fiscal year 2009. The majority of these funds will be allocated toward instructional materials for registered students. The remaining funds will be used for Advisory Services and Educational and Technical Research.

SOCIAL SECURITY ADMINISTRATION (SSA)

Limitation on Administrative Expenses – \$11.0 billion – The Limitation on Administrative Expenses (LAE) account provides resources for SSA to administer the Old Age, Survivors, And Disability Insurance (OASDI) and Supplemental Security Income (SSI) programs, and certain health insurance and Medicare prescription drug functions.

Because of years of persistent and cumulative under-funding for SSA, people with severe disabilities have experienced long delays and decreased services in accessing these critical benefits. People with severe disabilities who apply for Social Security disability benefits or for SSI benefits must wait months, and frequently years, for a decision. While they wait, homes are lost, families fall apart, and all resources are used up. Many have no health insurance and cannot afford critical medications and treatments, resulting in increased disability and even death.

In addition to the delays, the budget reductions have affected many other Social Security workloads resulting in increasing difficulties contacting the agency to report non-receipt of a check or to report earnings. The agency also has been forced to reduce the number of continuing disability reviews (CDRs). The processing of CDRs is necessary to protect program integrity and avert improper payments. CDRs result in \$10 of program savings for each \$1 spent in administrative costs for the reviews. The number of CDRs is directly related to whether SSA receives the funds needed to conduct these reviews. The inability to fully process these workloads is exacerbated by staffing shortages throughout the agency.

The problem has reached crisis proportions. Commissioner Astrue has made reduction – and elimination – of the disability claims backlog one of his top priorities. In Congressional testimony, he called it a “moral imperative.” While the current situation is dire, without adequate appropriations to fund SSA, the situation will deteriorate even more. We are encouraged by recent Congressional efforts to provide SSA with adequate funding for its administrative budget. The FY 2008 appropriation for SSA’s Limitation on Administrative Expenses (LAE) was \$9,746,953,000, an amount that was \$148 million above the President’s request and, for the first time in years, the agency received at least the President’s request. While the FY 2008 appropriation will allow the agency to hire some new staff and to reduce processing times, it will not be adequate to fully restore the agency’s ability to carry out its mandated services.

Due to the serious consequences of the persistent and cumulative under-funding of SSA’s administrative expenses, CCD recommends that SSA receive for its FY 2009 Limitation on Administrative Expenses (LAE), at a minimum, the President’s request of \$10.327 billion plus \$240 million. However, in order for SSA to meet its responsibilities, CCD estimates that the agency needs a minimum of \$11.0 billion for its FY 2009 administrative budget. This amount will allow the agency to not only significantly reduce the backlog, but also keep local offices open, provide adequate telephone services to the public,

and maintain the integrity of its programs by performing more continuing disability reviews and SSI redeterminations.

Protection and Advocacy for Beneficiaries of Social Security (PABSS) Program – \$14.0 million – The Ticket to Work and Work Incentives Improvement Act (TWWIIA) was enacted into law in 1999 with the goal of providing health care, employment preparation, and placement services to individuals with disabilities. As part of the Act, Congress authorized the Social Security Administration (SSA) to make payments to Protection and Advocacy agencies (P&As) to provide information and advocacy services to Social Security beneficiaries who want to work. The Social Security Administration began to fund the Protection and Advocacy for Beneficiaries of Social Security (PABSS) program in May, 2001

Since that time, the PABSS program has provided individuals with disabilities with the information, advice, advocacy, and other services they need to secure, maintain, or regain employment. Congress funded the PABSS program at \$7 million per year from 2001-2008. Secretary of Labor Chao has said that “the President’s New Freedom Initiative recognizes the tremendous contributions and potential of persons with disabilities and promotes greater job opportunities in high growth sectors of the economy, such as healthcare and advanced manufacturing.” While this is an admirable goal of the Administration, there are millions of Social Security and SSI beneficiaries with disabilities who need additional help just to get basic employment with adequate benefits. The PABSS program assists these individuals. The President’s FY 2009 proposes to level-fund the program at \$7 million. In reality, level funding is a cut and does not reflect the goals of the New Freedom Initiative. The CCD recommends a funding increase of \$7 million, for an FY 2009 funding level of \$14 million.

DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT (HUD)

Section 811 Supportive Housing for Persons with Disabilities – \$237.0 million – The Section 811 Supportive Housing for Persons with Disabilities program provides affordable and accessible housing for people with severe disabilities, including physical disabilities, developmental disabilities, and chronic mental illnesses as well as for all people with disabilities who currently live in institutions, nursing homes, homeless shelters, or who remain at home with aging parents because there is no housing available for them. Section 811 is the only federal program that funds the production of affordable and accessible units for persons with severe disabilities. The Administration’s FY 2009 budget proposes a mere \$160 million, slashing the program for a second consecutive year. This cut would virtually end the program’s production component. This proposed funding level will only support renewal of existing tenant-based and project-based subsidy commitments and minimal new units.

McKinney-Vento Homeless Assistance Act – \$2 billion – The President is requesting a \$146 million increase for programs under the McKinney-Vento Homeless Assistance Act for FY 2009, boosting funding to \$1.729 billion. This increase would continue efforts by the Bush Administration to move toward ending chronic homelessness by 2012. CCD endorses the goal of ending chronic homelessness and urges Congress to accelerate this effort and allocate \$2 billion for the McKinney Vento program for FY 2009. In addition, CCD supports efforts to keep in place the requirement for HUD to ensure that a minimum of 30% of McKinney-Vento funds are directed to permanent housing. This 30% permanent housing set aside has been critical toward ensuring that states and localities target resources to individuals with disabilities that have experienced long-term chronic homelessness. McKinney-Vento

permanent housing programs such as Shelter Plus Care and the Supported Housing Program (SHP) are extremely effective in breaking the costly cycle of the shelters, the streets, emergency rooms and jails that is associated with chronic homelessness. Congress should not back away from this critical investment.

Vouchers Targeting Non-Elderly Persons with Disabilities- \$50 million - Section 8 vouchers, which are administered by Public Housing Agencies, are designed to bridge the gap between income and rent by paying the difference between what a very low-income household can afford (e.g., 30 percent of income) and modest rental housing costs. In FY 2008 Congress appropriated \$30 million for approximately 4,000 new vouchers targeted to non-elderly people with disabilities. This was the first time since 2002 that Congress has provided such funding. The Administration's FY 2009 budget contains no funding for additional new vouchers.

DEPARTMENT OF VETERANS AFFAIRS (VA)

The U. S. has been at war in Iraq, Afghanistan and related combat staging locations for almost seven years. Over 1.4 million service men and women have been deployed in the global war on terror. According to the Department of Veterans Affairs (VA), in the first six months of FY 2007, it treated almost 124,000 new veterans – a 29 percent increase over FY 2006. Although the Administration recommended increases in funding for the Department of Veterans Affairs (VA), including VA health care, the funding levels fall short of the resources necessary to provide adequate health care and benefits for veterans as recommended by *The Independent Budget (IB)*, a comprehensive budget policy document co-authored by the AMVETS, Disabled American Veterans, Paralyzed Veterans of America and the Veterans of Foreign Wars. Because veterans with disabilities are people with disabilities, CCD recognizes the importance of assuring that the programs designed for these veterans receive the resources necessary to provide quality care and service. CCD also understands that an inadequately funded VA will only increase costs in other federal programs to which veterans with disabilities will have to turn for assistance if they are shut out of the VA.

Veterans Health Administration - \$43.377 billion – VHA includes Medical Services, Medical Administration, Medical Facilities and Medical and Prosthetic Research. The Administration requested approximately \$41.2 billion, \$1.6 billion less than the level supported by major veterans' organizations to provide adequate health care for all veterans. CCD supports the level proposed in *The Independent Budget (IB)* of \$42.8 billion for Medical Services, Medical Administration and Medical Facilities. For Medical and Prosthetic Research, the Administration has recommended \$442 million, a cut of approximately \$38 million below the FY 2008 appropriation. CCD agrees with *The Independent Budget (IB)* recommendation of \$555 million because research is a vital part of veterans' health care, and an essential mission for our national health care system.

General Operating Expenses - \$1.985 billion - GOE includes the administrative budget of the VA and the Veterans Benefits Administration. A core mission of the VA is to provide disability compensation to service-injured veterans and pension to low-income veterans and their dependents and survivors. Yet, the backlog of compensation claims continues to grow from a level of over 600,000 in 2006 to over 650,000 by March, 2008. The VA must be provided with sufficient staffing and other administrative resources to offer veterans and their families timely and accurate decisions.

DEPARTMENT OF TRANSPORTATION

Section 5310 Program – 133.5 million – The goal of the Section 5310 program is to improve mobility for elderly individuals and individuals with disabilities throughout the country. Toward this goal, the Federal Transit Administration provides financial assistance for transportation services planned, designed, and carried out to meet the special transportation needs of elderly individuals and individuals with disabilities in all areas—urbanized, small urban, and rural. The program requires coordination with other Federally-assisted programs and services in order to make the most efficient use of Federal resources. State governments are responsible for implementing the program. The CCD FY 2009 recommendation is consistent with the SAFETEA-LU authorized levels for this program.

New Freedom Program – 92.5 million - The New Freedom Program (NFP) was created under SAFETEA-LU, enacted on August 10, 2005. The NFP supports new public transportation services and public transportation alternatives beyond those required by the Americans with Disabilities Act of 1990 that assist individuals with disabilities with their transportation needs, including transportation to and from jobs and employment support services. SAFETEA-LU also established coordination planning requirements for the NFP, the Elderly Individuals and Individuals with Disabilities program (Section 5310) and the Job Access and Reverse Commute program. The CCD FY 2009 recommendation is consistent with the SAFETEA-LU authorized levels for this program.

Project ACTION – 3 million - The strength of Project ACTION is its continued effectiveness in meeting the congressional mandate to work with both the transit and disability communities to create solutions that improve access to transportation for people with disabilities of all ages and to assist transit providers in complying with transportation provisions in the Americans with Disabilities Act. Congress authorized assistance to Project ACTION in 1990 with the passage of ISTEA and reauthorized the project in 1997 as part of TEA-21 and in 2005 as part of SAFETEA-LU. The CCD FY 2009 recommendation is consistent with the SAFETEA-LU authorized levels for this program.

KEY DISABILITY ENTITLEMENT PROGRAMS

In addition to those programs that are funded via the Congressional appropriations process, people with disabilities are also served by two major entitlement programs, Medicaid and Medicare. Between the two, they provide a virtual “lifeline” to people with disabilities and health care, long-term services and supports, and other assistance necessary to help people live and thrive in their communities. Below are brief descriptions of each of these vital programs.

Medicaid

Medicaid, which is financed and administered jointly by the federal government and the states, is the most valuable resource for children and adults with disabilities to access health and long-term supports and services in the community. The nation’s largest program serving the needs of low-income Americans with disabilities, Medicaid serves 10.3 million people with disabilities. Roughly three-fourths of Medicaid recipients with disabilities are considered “mandatory beneficiaries” as recipients of Supplemental Security Income benefits (SSI). People with disabilities above SSI income and resource levels are “optional” beneficiaries. Medicaid offers certain mandatory services, such as hospital, physician, and nursing home services. States can also choose to offer optional services, including prescription drugs; physical therapy and related services; diagnostic screening and preventive services; home and community based services; case management services; prosthetic devices; personal care services; rehabilitative services; dental care; vision care; Intermediate Care Facilities for people with mental retardation and related conditions (ICF/MR); and hospice care. At a minimum, states must offer mandatory services to the mandatory eligibility groups. Generally, when states add optional services or populations to their Medicaid plans, they must make available to any eligible person any of the services the individual needs (except for people who are categorized as medically needy or who are receiving services under a waiver).

Over the past year, the Centers for Medicare and Medicaid Services (CMS) has issued seven Medicaid rules, in either proposed or final form, which together would have a devastating impact on Medicaid beneficiaries and the safety net providers that serve them. Taken together, these rules will reduce federal financing for Medicaid by \$15 billion over five years. The President’s FY 09 budget proposes \$17.4 billion in legislative changes to Medicaid over five years and additional administrative rules are likely pending. These regulatory changes will shift significant Medicaid costs to states at a time when the economy is in a downturn and many states are either experiencing declining revenues—or bracing for revenues to start falling. Preventing implementation of these regulations is the top priority for all Medicaid stakeholders, including the disability community.

Three of the seven rules will be particularly harmful to Medicaid beneficiaries with disabilities and their providers. If implemented, these regulations will result in the loss of critical services for Medicaid eligible children and adults with disabilities.

1) Rehabilitation Services Option

CMS issued a proposed rule on 8/13/07 which would generate \$2.3 billion in savings over 5 years by restricting the scope of eligible rehabilitation services and eliminate coverage for day habilitation services for individuals with developmental disabilities. The Medicaid rehabilitation services (rehab) option is an essential tool used by nearly all states. For example, the unique flexibility of this option enables states to provide proven, evidence-based treatment for people with serious mental

illnesses that keeps them out of hospitals and living successfully in the community. The Bush Administration's rule threatens states' capacity to operate such programs.

2) School-Based Administrative and Transportation

CMS issued a final rule on 12/28/07 that would generate \$2.8 billion in cuts over 5 years by prohibiting Medicaid payments for administrative activities (including outreach, enrollment and support in gaining access to Medicaid's Early, Periodic, Screening, Diagnosis and Treatment (EPSDT) benefits services) performed by schools and transportation of school-age children. School districts believe that this rule, if implemented, would force them to significantly reduce related services (e.g. physical, occupational and speech and language therapies) and classroom aides provided to students with disabilities in special education.

3) Case Management

CMS issued an interim final rule on 12/04/07 that became effective on 03/03/08 and will result in \$1.3 billion in cuts over five years by restricting the scope of case management services and targeted case management (TCM). The TCM rule makes it significantly more difficult for individuals transitioning from institutions to the community by limiting federal reimbursement for transitional case management from the last 180 days of an individual's institutional stay to the last 60 days. In many cases, due to the lack of affordable and accessible housing and challenges in securing support services, it is difficult to impossible to transition to the community in 60 days.

By the Administration's own estimate, these three programs would be cut by a combined total of \$7 billion over five years - and the other rules would cut Medicaid further, shifting costs onto states at a time of growing state economic distress. These funding reductions threaten access to vital medical, social, and educational services.

Medicare

Approximately 6.5 million people with disabilities under age 65 receive Medicare benefits. To qualify, an individual must meet the Social Security Administration's standard for long-term, serious disability. Most Medicare beneficiaries with disabilities under age 65 have worked but have become disabled and now receive Social Security Disability Insurance (SSDI) payments. Most people with disabilities under age 65 must wait two years from when they are determined to be eligible before their Medicare coverage becomes effective. Other Medicare beneficiaries with disabilities become eligible as "Disabled Adult Children" (i.e. they receive Social Security benefits and Medicare due to the retirement, death, or disability of a parent.) "Dual Eligibles" are those who receive both Medicare and Medicaid benefits.

The President's budget proposes to significantly reduce Medicare spending by \$178.2 billion over five years. Much of the Medicare savings, approximately \$117 billion, would come from reducing scheduled reimbursement increases in provider payments over the next five years. For example, inpatient rehabilitation facilities would be cut by \$4.8 billion.

CCD believes that with so many major improvements critically needed in the Medicare program, these proposals are misplaced. Congress should be focused on fixing the problems with implementation of the Part D drug benefit; extending reasonable treatment of Medicare beneficiaries whose outpatient therapy needs exceed the caps set to apply in full force next year; averting a significant decrease in the physician fee schedule; modifying the "in the home" restriction under the durable medical equipment benefit so that people requiring wheelchairs are not confined to the four walls of their homes; and eliminating Medicare's 2-year "waiting period". CCD believes that further restrictions in funding to the Medicare program would be ill-advised at this time.