Outline of the Evolution of The Developmental Disabilities Assistance and Bill of Rights Act

by Allan I. Bergman
United Cerebral Palsy Associations, Inc.

1963 **P.L. 88-164**
Mental Retardation Facilities and Community Mental Health Centers Construction Act (as a result of President Kennedy's forming the President's Panel on Mental Retardation).

- Began research centers which have become the University Affiliated Program (UAP);
- Provided financial aid for community facilities;
- Provided construction dollars.

1967 **P.L. 90-170**
Mental Retardation Amendments of 1967.

- Provided grants for training and staffing community facilities for people with mental retardation;
- (1968 and 69 funds impounded -- Vietnam conflict).

1970 **P.L. 91-517**
Mental Retardation Act amended and renamed Developmental Disabilities Services and Facilities Construction Act

- Adopted categorical definitions -- mental retardation, cerebral palsy, epilepsy and other severe neurologically handicapping conditions with an age of onset before 18 years;
- Established Governors' Councils on Developmental Disabilities to do planning.

1975 **P.L. 94-103**
Developmental Disabilities Assistance and Bills of Rights Act

- Added Bill of Rights in treatment, services and habilitation;
- Created the Protection and Advocacy System as a requirement in each State by October 1, 1977;
- Added autism as a new categorical group;
- Created Commission to study definition.

1978 **P.L. 95-602**
Developmental Disabilities Amendments of 1978

- Adopted the current functional definition of

developmental disabilities with an age of onset of 22 and no reference to mental retardation, but rather to mental and/or physical impairments;
- Defined priority areas for State Developmental Disabilities Councils.

1984 **P.L. 98-527**
Developmental Disabilities Amendments of 1984

- Established Independence, Productivity and Community Integration as the goals of State service systems for persons with developmental disabilities and as the mission for Developmental Disabilities Councils, Protection and Advocacy agencies and UAP's;
- Mandated employment as a Council priority.

1987 **P.L. 100-106**
Developmental Disabilities Amendments of 1987

- Clarified Developmental Disabilities Council's role in systems advocacy and public policy;
- Clarified independence of Council and Council staff from administering agency;
- Required Developmental Disabilities Councils to conduct consumer satisfaction surveys, comprehensive service system analysis, public forums and recommendations for system change re unserved and underserved populations (generally persons without mental retardation) to be sent to Governor and State Legislature by January 1, 1990 and to Congress by April 1, 1990.

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UNITED CEREBRAL PALSY ASSOCIATIONS

Word from Washington

Senators Tom Harkin (IA) and Robert Dole (KS) are expected to take a leadership role in the U.S. Senate on disability issues in 1991.

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November/December 1990

The 101st Congress in Review

by Allan I. Bergman
Patricia Brady
Christopher Button
Bob Griss
Michael Morris
Bob Williams

As we take time to reflect on the past two years of public policy debate in the United States Congress, people with disabilities and their families and advocates will be able to look back at their many accomplishments that didn't get the major headlines of the press—not John Tower's nomination, Oliver North's trial, the Savings & Loan scandal, the Keating Five, Iraq's invasions of Kuwait and so many more. For us, the 101st Congress will go down in history for passage of The Americans With Disabilities Act (P.L. 101-336), signed by President Bush on July 26, 1990. This landmark civil rights legislation sets the tone in public policy for the remainder of the twentieth century. It declares that *all* persons with disabilities are citizens of the United States of America.

The new anti-discrimination provisions in employment, public transportation, public accommodation, public services and telecommunications will be implemented through regulations currently being developed by the Equal Employment Opportunity Commission, the U.S. Department of Justice and the Federal Communications Commission. The law and regulations will create wide vistas of new opportunities for American citizens with disabilities to have choices and to learn, live, work, play and participate in inclusive community life.

In this, the final issue of *Word From Washington* in 1990, we are providing you an overview of the major decisions of the 101st Session of Congress and trust it will serve as a convenient reference to you for your local and state advocacy agendas. As appropriate, we are providing you with suggested advocacy implementation activities at the end of each article on a major piece of legislation.

Winners of the 101st Congress

THE AMERICANS WITH DISABILITIES ACT (ADA, P.L. 101-336) The Americans with Disabilities Act (ADA), signed into law by President Bush on July 26 1990, prohibits discrimination based on disabilities in the areas of employment, public services, transportation, public accommodations and telecommunications. This law will affect the lives of more than 43 million Americans by requiring all affected entities to provide "reasonable accommodation" to persons with disabilities.

Employers, employment agencies, labor organizations and joint labor management committees will be prohibited from discrimination against any qualified individual with a disability with regard to job application procedures; hiring, advancement or discharge; employee compensation; job training; and other terms, conditions or privileges of employment.

Discrimination on the basis of disabilities is prohibited in all programs, activities and services provided or made available by state and local governments regardless of whether or not those entities receive federal financial assistance.

Businesses that provide services to the general public, as well as public and private entities that provide public transportation services are prohibited from discriminating on the basis of disability and must provide full and equal enjoyment of goods, services, facilities, privileges, advantages and accommodations to individuals with disabilities.

Commercial facilities and places of public accommodations, including but not limited to places of lodging, restaurants, theaters and concert halls, banks, barber shops, museums and libraries, nursery schools and day care centers, and offices of accountants, lawyers, and health care providers, are required to be made accessible for people with disabilities.

Telephone services offered to the general public must include interstate and intrastate telecommunications relay services so that these services provide individuals with disabilities access to communications equivalent to those provided to individuals able to use voice telephone systems.

Private individuals, the Equal Employment Opportunity Commission, and the Department of Justice have authority to bring actions in court to enforce compliance with the mandates of ADA.

IMPLEMENTATION ACTIVITIES:

- *Obtain a copy of P.L. 101-336 and House Report 101-596 from your U.S. Senator or Congressperson.*
- *Submit your concerns on ADA regulations to the appropriate federal agency and monitor the regulatory process:*
  - *(a) Title I, Employment Discrimination, by the Equal Employment Opportunity Commission (EEOC), 1801 L Street, NW, Washington, DC 20507. Tel: (202)-663-4264;*
  - *(b) Titles II & III, Public Services and Public Accommodation by the U.S. Department of Justice, Civil Rights Division, Coordination and Review Section, P.O. Box 66118, Washington, DC 20035-6118. Tel: (202) 514-0301 (voice), (202) 514-0381 (TDD) and (202) 514-0383 (TDD);*
  - *(c) Title IV, Telecommunications, by the Federal Communications Commission (FCC), 1919 M Street, NW, Washington, DC 20554. Tel: (202) 632-7129.*
- *Develop local and state coalitions and begin working with the private sector on "win-win" implementation of the ADA.*
- *Conduct information and education programs for persons with disabilities and their families to know their rights.*

DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT OF 1990 (P.L. 101-496) On October 31, 1990, President Bush signed into law the 1990 amendments to the Developmental Disabilities Assistance and Bill of Rights Act, which was first enacted in 1970. This legislation authorizes the Governor-appointed Councils on Developmental Disabilities in each state, the State Protection & Advocacy System, the University Affiliated Programs and Programs of National Significance administered by the Administration on Developmental Disabilities within the Department of Health & Human Services.

Among the major amendments to the Law are the following—

- Adds the goals of "interdependence", "community acceptance", and "inclusion" to the Purposes Section of the law to further refine the goals of "independence", "productivity" and "integration" enacted in 1984 as the goals of services for all people with developmental disabilities.
- Replaces and expands the State plan priority area of "case management" to "System Coordination and Community Education" with a focus on eliminating barriers to access, enhancing systems design and individual, family and citizen involvement.
- Requires the State Developmental Disabilities Planning Councils to build upon their 1990 reports (as required in the 1987 Developmental Disabilities Act Amendments promoted by UCPA) of unserved and underserved people in relation to services and supports in future State plans and priorities by:
  (a) including a "Summary of Actions Taken" in regard to 1990 Report results;
  (b) requiring an analysis of the special and common needs of all subpopulations of persons with developmental disabilities;
  (c) requiring the use of information in the 1990 report in its decisionmaking process about priority areas as well as selection of activities to conduct to create system change; and
  (d) requiring that 65 percent of each State's allotment used for priority areas include activities to implement the recommendations made in the 1990 Report including those which address unserved and underserved populations;
  (e) requiring an assessment, update and progress report on meeting the needs of unserved and underserved people in the 3-year plan.
- Mandates the annual statement of objectives by the Protection & Advocacy System in each State.
- Expands the ability of the Protection & Advocacy System to access records in selected situations of potential harm.
- Requires the establishment of a community advisory committee at every University Affiliated Program.
- Expands the University Affiliated Program training initiatives to include assistive technology and positive behavior management.
- Establishes criteria for training at University Affiliated Program's including value-based and competency-based components.

IMPLEMENTATION ACTIVITIES:

- *Obtain and review a copy of your State Developmental Disabilities Council's 1990 report.*
- *Attend meetings of your State Council to assure that its members and staff know your issues.*
- *Monitor the development of annual priorities and activities to assure the inclusion of persons with developmental disabilities attributable to physical impairments.*
- *Obtain and review the annual statement of objectives from your State Protection and Advocacy System.*
- *Attend annual public meetings of your State Protection and Advocacy System to influence its priorities.*
- *Contact your University Affiliated Program regarding membership on its Community Advisory Committee.*
- *Encourage your University Affiliated Program to pursue a training grant on assistive technology.*

INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA, P.L. 101-476) On October 30th, 1990, the President signed into law the reauthorization of discretionary programs of what since 1975 was named The Education of All Handicapped Children Act. Included in the reauthorization are several substantive amendments which will significantly improve supports and services to students with disabilities. Of particular interest for students with cerebral palsy and other severe disabilities are the following amendments:

Transition Mandated in IEPs

- A definition of transition services was added:
  "(A) coordinated set of activities for a student, designed within an outcome-oriented process, which promotes movement from school to post-school activities, including post-secondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation. The coordinated set of activities shall be based upon the individual student's needs, taking into account the students preferences and interests, and shall include instruction, community experiences, the development of employment and other post-school adult living objectives, and, when appropriate, acquisition of daily living skills and functional vocational evaluation."
- Provisions were added to require inclusion of a statement of needed transition services for students within the Individualized Education Program (IEP), beginning no later than age 16 and, when appropriate, beginning no later than age 14 or younger.
- A new competitive grant authority was created for joint applications by state education agencies and state rehabilitation agencies to provide transition services.

Assistive Technology

- Assistive technology is now defined and included throughout the Act to assure that students in need of assistive technology services receive them from trained personnel.

Waiver of State Sovereign Immunity

- Congress reversed the *Dellmuth v. Muth* (1989) decision by including a new section (Section 604) which clarifies Congressional intent that States are not immune under the Eleventh Amendment from suit in federal court for violation of the Individuals with Disabilities Education Act.

Minority Provisions

- A priority was established to train minority personnel. Grant applications are required now to include in their applications a detailed description of strategies that will be used to recruit and train members of minority groups.
- Priority will be given to minority students for receipt of fellowships or traineeships.
- Parent training centers are now required to include minority parents and professionals on the boards of these centers and their programs.

Terminology

• **Access to Telecommunications.**
Title IV of the ADA added a new Section 225 to the Communications Act of 1934, creating a right to access to the nation's telecommunications network on behalf of TDD users; however, the legislation does not expressly require access for other persons, such as people with cerebral palsy, who are denied equal access to the telecommunications network. Discussions are underway to introduce legislation to redefine "universal access" in the Telecommunications Act of 1934 as well as legislation to lift the restrictions which now prevent the seven "Baby Bells" from originating information services, manufacturing equipment and related areas since these restrictions are viewed as hindering progress toward an accessible telecommunications network.

UCPA LEGISLATIVE POLICY PROCESS During the past few weeks, UCPA key volunteers and affiliate executive directors received a survey to rank priorities for the 102nd session of Congress. In addition, these same individuals will receive in-depth surveys on both the reauthorization of the Rehabilitation Act and Part H of P.L. 99-457. All of these data will be analyzed and reported for deliberation by the UCPA's twelve-member national Governmental Activities Committee during their meeting in Washington, D.C., in February 1991. This UCPA committee will develop and adopt a UCPA legislative 'Platform and Priorities' for the 102nd session of Congress which becomes the marching orders for UCPA's Governmental Activities staff. The Platform will be published in the January/February 1991 issue of *Word From Washington*.

Word From Washington **is published by United Cerebral Palsy Associations, Inc., Seven Penn Plaza, Suite 804, New York, NY 10001, Leonard H. Goldenson, chairman; Jack Hausman, vice chairman; Martin Rubenstein, vice chairman; Robert J. MacDonald, president; John D. Kemp, executive director; Michael W. Morris, associate executive director, Community Services Division; Allan I. Bergman, deputy director; Patricia Brady, Christopher Button, Bob Griss, Bob Williams, staff; Jenifer Simpson, administrative assistant.**

Word from Washington

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- Terminology was changed to people-first language. "(H)andicapped children" is replaced with "children with disabilities" throughout.
- The name of the Act is changed from the Education of the Handicapped Act (EHA) to the Individuals with Disabilities Education Act (IDEA).

IMPLEMENTATION ACTIVITIES:

- *Obtain a copy of P.L. 101-476 from your U.S. Senator or Congressperson.*
- *Inform parents of students receiving publicly financed special education services (Kindergarten through Grade 12) regarding the new mandate for transition services to be included in the IEP and the definition of transition services.*
- *Encourage your state education and rehabilitation agencies to jointly apply for competitive grant funds when they become available later this year; be sure that persons with disabilities and parents are included in such projects.*
- *Inform parents of students receiving publicly-funded special education services for the requirement for assistive technology to be included as part of the IEP as defined in Office of Special Education Director Judy Schrag's policy letter of August 10, 1990 (see WFW, Sept./Oct. 1990).*

NATIONAL AFFORDABLE HOUSING ACT (P.L. 101-625) On November 28, 1990, President Bush signed into law the Cranston-Gonzales National Affordable Housing Act (NAHA), now P.L. 101-625. This major omnibus housing legislation has the potential to positively impact the lives of persons with disabilities. The legislation makes some potentially substantive modifications to the present Section 202 Program and includes other provisions to improve both the quantity and quality of available housing options. However, as with any new legislation, this will only be as successful as it is implemented and funded.

Understanding the purposes of the NAHA can do much to increase the availability of affordable housing options for persons with disabilities if those with an interest in acquiring and/or developing housing become familiar with the major components of the law. These purposes relate to home ownership; the retention of presently available affordable dwelling units for low-income families; the extension and strengthening of partnerships at all levels of government and in the private sector; including for-profit and non-profit organizations in the production and operation of housing; the expansion and improvement of federal housing assistance; and an increased supply of supportive housing which meets the needs of so-called "special populations" to live with both dignity and independence.

Title VIII of the Act completely separates the old Section 202 program for persons who are elderly (over 62 years of age) from that for people with disabilities and names it "Supportive Housing for Persons with Disabilities." A major change in the Section 202 program provides to non-profits a capital advance rather than a loan for the purchase of existing properties or new construction of group homes, independent living complexes or apartments. A non-profit could apply for funds for the purchase of condominiums or cooperatives and also receive rental assistance payments for the residents. The law requires that the program support housing options which provide "opportunities for optimal independent living and facilitate ... participation in the community at large," and limits group homes to no more than eight persons. As long as the property remained available for low income persons with disabilities, the non-profit will not be expected to repay the advance. Existing projects with a Section 202 fund reservation are eligible for a conversion of their loan funds to a capital advance, based upon HUD approval, although the new program of "supportive housing" will not be effective until October 1, 1991.

An article in the January/February 1991 *Word From Washington* will detail the specific requirements of NAHA and how best UCPA and other advocates can influence its implementation through the regulatory process.

IMPLEMENTATION ACTIVITIES:

- *Obtain a copy of P.L. 101-625 and the Conference Report from your U.S. Senator or Congressperson.*
- *Carefully study all of the provisions on Title VIII.*
- *Review any pending HUD 202 loan commitments for projects not yet begun and consider applying for a cash advance instead.*
- *Monitor the federal regulatory process for the National Affordable Housing Act as administered by HUD.*
- *Discuss the "Supportive Housing for Persons with Disabilities" provisions for 1991-1992 with people with disabilities, family members, and persons in the private sector for possible collaborative applications under the new law.*

CHILDREN WITH DISABILITIES TEMPORARY CARE REAUTHORIZATION ACT OF 1989 (P.L. 101-127) Originally enacted as Title II of the Children's Justice and Assistance Act of 1986 (P.L. 99-401), this legislation was first funded at $4.7 million in FY 1988 as the Temporary Child Care for Handicapped Children and Crisis Nurseries Act. The original policy of the legislation was based on the data that children with disabilities have been shown statistically to be at high risk of "child abuse or parental neglect."

Testimony at the hearings, conducted in April 1989 by the House Subcommittee on Select Education shifted the emphasis to the value of respite care for families with a child with a disability. Amendments to the legislation in 1989 (P.L. 101-127) extends the program through September 30, 1991; requires the States competing for the grant funds to provide interagency coordination and the development of a State plan across all State agencies receiving selected federal funds; requires States to document parental satisfaction with the service; and raises the authorization level to $20 million per year. The program received $11 million for FY 1991.

IMPLEMENTATION ACTIVITIES:

- *Obtain a copy of P.L. 101-127 from your U.S. Senator or Congressperson.*
- *Contact your Governor's Office to determine the name of the designated State agency and contact person for the "Children With Disabilities Temporary Care Reauthorization Act of 1989.*
- *If your State already has received one or more competitive grants, contact the provider(s) to determine the scope of the project.*

- *Obtain copies of the State plan and parental satisfaction survey form and data.*
- *Encourage your State agency and Governor to support reauthorization of the Act this year (see page 14 of this issue of WTW.)*

TELEVISION DECODER CIRCUITRY ACT (P.L. 101-431) The Television Decoder Circuitry Act sponsored by Senator Tom Harkin (IA) requires televisions with screens of 13 inches or larger to have built-in decoder circuitry for the display of closed-captioned television transmission by July 1, 1993. Built in decoder circuitry will dramatically reduce the cost of the decoder for audiences that need to receive closed-captioned television. Mass production of the decoders will cost an estimated three to five dollars per television.

The law will assure that people wanting to see captions on programs that provide them can do so by merely flipping a switch on their sets. The potential audience for closed-captioned programming for individuals with communication disabilities is estimated to be more than 24 million.

EPSDT IMPROVEMENTS (P.L. 101-239) Expansions to the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program were passed by Congress as part of OBRA'89. OBRA'89 amended Section 1902(a)(43) and 1905 (A)(4)(B) and created Section 1905(r) of the Social Security Act which sets forth the requirements for the program. Under what is now a "federal" rather than a state/federal EPSDT benefit, a State must provide physical, developmental, vision, hearing and dental screening services at intervals which meet reasonable standards of medical and dental practice. States also must provide medically necessary screening, vision, hearing, and dental services regardless of whether such services coincide with their established periodicity schedules for these services. Most importantly, the Act requires that any service which States are permitted to cover under federal Medicaid policy that is necessary to treat or ameliorate a defect, physical and mental illness, or a condition identified by a screen, must be provided to EPSDT participants regardless of whether the services or item is otherwise included in the State's Medicaid plan, and do so without any arbitrary standards to limit amount, scope and duration of a service. This program is of phenomenal importance to expand federal funding for a wide range of services to children with disabilities eligible for Medicaid, including therapies, eyeglasses, hearing aids, wheelchairs, nursing services, augmentative communication devices, and so many more.

In April, 1990, HCFA published a State Medicaid Manual Issuance to implement the new provision for the EPSDT program. The amendments went into effect on April 1, 1990.

Because of the significant role which Medicaid EPSDT funding can play in the implementation of early intervention and preschool services, Congress addressed this issue in the Labor, Health & Human Services, Education Appropriations bill report for FY 1991. The Appropriations Committee, (in Senate Report 101-516) directed the Departments of Education and Health & Human Services "to develop a joint policy statement containing consistent information and uniform procedures to enable Medicaid, Part B and Part H agencies and health care providers to work together in helping children, infants and toddlers with disabilities to obtain the full benefits of Federal Programs."

IMPLEMENTATION ACTIVITIES:

- *Obtain a copy of the OBRA '89 amendments to EPSDT by calling Jenifer Simpson @ (800) USA-5UCP or (202) 842-1266.*
- *Meet with families, advocates and providers at the local level to plan strategies for working together for full implementation of the EPSDT mandated entitlements.*
- *Arrange to meet with your State's Medicaid Director and staff to determine the status of implementation of these amendments.*
- *Obtain a copy of the State Medicaid plan or manual for EPSDT.*
- *Disseminate information widely on this important service and financing program for infants, toddlers, preschoolers and children to age 19 and their families.*

LIMITED SSDI WORK INCENTIVE (P.L. 101-239) Early in the 101st Congress, a limited work incentive program for people with disabilities who receive Social Security Disability Insurance became law as part of the OBRA'89.

The provision allows SSDI recipients with disabilities who return to work to purchase Medicare insurance coverage after they have exhausted their trial work period (12 months) and the extended period of eligibility (36 months).

The law also requires Medicaid to pay the premium for SSDI recipients earning less than 200 percent of poverty ($11,960 annually in 1989). For those earning between 150 and 200 percent of the poverty line, states could require the individuals to pay part of the premium. For SSDI recipients earning over 200 percent of poverty, the individuals would pay the entire premium. The work incentive, which went into effect April 1, 1990, will assist some individuals who receive SSDI in returning to gainful employment while retaining health insurance.

CARL D. PERKINS VOCATIONAL AND APPLIED TECHNOLOGY EDUCATION ACT (P.L. 101-392) On September 25th, 1990, President Bush signed P.L. 101-392 authorizing amendments to the Carl D. Perkins Vocational Education Act. These amendments established a new system of distributing funds for secondary vocational education programs. They do not maintain the set-asides which existed previously for special populations including a former ten percent set-aside for persons with disabilities. Instead, the amendments stipulate that individuals who are members of special populations must be provided with equal access to recruitment, enrollment, and placement activities, as well as equal access to the full range of vocational education programs available to individuals who are not members of special populations [illegible]

tional education must be provided to individuals with disabilities in the least restrictive environment, and must, where appropriate, be included as part of the individualized education plan (IEP).

IMPLEMENTATION ACTIVITIES:

- *Obtain a copy of P.L. 101-392 from your U.S. Senator or Congressperson.*
- *Contact your State board for vocational education to determine the dates and locations for the public hearings to discuss the State's three-year plan required by the law.*
- *Review the draft state plan to determine the adequacy of the required state assurance statements for "equal access" in all areas for people with disabilities.*
- *Contact local education agencies and postsecondary institutions to assure their plans call for the inclusion of students with disabilities and the availability of supportive services for students with disabilities.*

NATIONAL AND COMMUNITY SERVICE ACT OF 1990, P.L. 101-610 The National and Community Service Act of 1990 was approved in the last days of the 1990 session of Congress. Action on the legislation, which comes after years of efforts by advocates for National Service, authorizes a variety of national and community service learning programs. The measure, introduced by Senators Edward Kennedy (MA) and Orrin Hatch (UT), and Congressman Augustus Hawkins (CA), was passed in the Senate by a 75 to 21 vote on October 16, and in the House, by a 235 to 186 margin on October 24. It was signed by President Bush on November 16, 1990.

The Act authorizes $287 million for its various grant programs over the next three years: $62 million for 1991, $105 million for 1992 and $120 million for 1993. Funds for 1991 have been authorized as follows: $54 million for Kindergarten through 12th grade Service Learning Programs and Post-Secondary Education Innovative Projects for Community Service, $2 million for the Commission on National and Community Service (including four regional clearinghouses), $5 million for the President's Points of Light Foundation and $1 million for the Youthbuild program. Each of the programs will experience an increase in the funding over the next three years, with the exception of the Commission on National and Community Service.

In signing the Act, the President said, "There can be no nobler goal than to strengthen the American ethic of community service and to help translate this ethic into meaningful action."

IMPLEMENTATION ACTIVITIES:

- *Obtain a copy of P.L. 101-610 from your U.S. Senator or Congressperson.*
- *Determine if your state or local education agency or postsecondary education agencies plan to apply for these new community service funds. Encourage them to do so.*
- *Be sure that any local or state efforts include both community service to students with disabilities and participation by persons with disabilities with the necessary supportive services.*

OMNIBUS BUDGET RECONCILIATION ACT OF 1990 (OBRA) P.L. 101-508 Congress completed work on the five-year budget package on October 27th and President Bush signed the Omnibus Budget Reconciliation Act of 1990 (OBRA '90) on November 5th, as P.L. 101-508. The sweeping measure proposes to reduce the projected deficit by $496.2 billion over five years. The voluminous law contains many provisions impacting people with disabilities and their families. It also includes many changes in the Gramm-Rudman deficit reduction process which will impact appropriations for the next five years. The following items represent several major legislative changes in OBRA.

MEDICAID

Improvements in Child Health

Phased-in mandatory coverage of children up to 100 percent of poverty level. Under current law, States are required to cover children up to age 6 in families with incomes under 133 percent of the Federal poverty level and have the option to expand income eligibility to 185 percent of poverty level. States are permitted to cover children born after September 30, 1983 up to 7 years old (or 8 at State's option) in families with incomes below a State-established income level which may be as high as 100 percent of the Federal poverty level. The new law now requires States to cover children up to age 19 up to 100 percent of poverty level by the year 2003, beginning at age 7 on July 1, 1991.

Mandatory continuation of benefits throughout pregnancy or first year of life. The new law will require all States to continue eligibility for pregnant women until the end of the second full month beginning after the end of pregnancy, except in the case of a women who has been provided ambulatory care during a presumptive eligibility period and then determined to be ineligible. The law also provides that infants born to women who are eligible for Medicaid remain eligible until their first birthdays.

Previously, States had the option of continuing coverage for a pregnant women through the end of the second full month beginning after the end of pregnancy, even if the women would otherwise become ineligible during that period. The child is eligible for Medicaid as long as the women remains eligible.

Mandatory use of outreach locations other than welfare offices. Under current law, States determined the sites at which applications for Medicaid would be accepted. The new provision requires States to accept and begin processing applications by pregnant women and children under 18 at locations other than welfare offices, such as clinics, hospitals, neighborhood health centers, etc.

IMPLEMENTATION ACTIVITIES:

- *Contact your State Medicaid agency to determine the dates of implementation of the new mandates and options for eligibility expansion for children.*
- *Disseminate the information on mandated expansions widely at the local and state level, especially to providers of services to children from low-income families or children who are eligible for SSI benefits.*

- *Determine which centers, clinics and agencies in your community could fulfill the function of outreach and assist that agency (ies) in becoming a state-approved Medicaid outreach application center.*

COMMUNITY SUPPORTED LIVING ARRANGEMENTS SERVICES (CSLA, P.L. 101-508) The OBRA of 1990, Section 4712, established a new limited option under the Medicaid program to permit from two to eight States to provide "community supported living arrangements services" The purpose of the program is to assist eligible persons in the activities of daily living necessary to permit them to live in the community. The service is limited to individuals with developmental disabilities **without regard to whether such individuals are at risk of institutionalization. This requirement represents a major Medicaid policy change by no longer linking the receipt of Medicaid funds for community living to institutional admission criteria and standards.**

Definition of Community Supported Living Arrangements Services The law defines "community supported living arrangements services" to mean one or more of the following services designed to assist an individual in activities of daily living necessary to permit such individual to live in the individual's own home, family home, or rental unit, Services may include **personal assistance;** training and habilitation services necessary to assist the individuals in achieving increased community integration, independence, and productivity; 24-hour emergency assistance; **assistive technology and adaptive equipment to help overcome the effects of impairments;** support services necessary to aid an individual to participate in community activities; and other non-excluded services as approved by the Secretary. Excluded services are room and board, and the cost of prevocational, vocational, and supported employment services.

Definition of Developmentally Disabled Individual "Developmentally disabled individual" is defined to mean an individual defined by the Secretary within the term "mental retardation and related conditions" as set forth in regulations in effect on July 1, 1990. In addition, the individual must reside in his or her own home or in the family home, apartment, or other rental unit in which no more than three other individuals receiving these services reside.

Participating States The Secretary is required to develop criteria for the review of applications from States requesting funds to provide community supported living arrangement services. During the first 5 years of the program, no less than two and not more than eight States are allowed to participate in this program.

Quality Assurance States participating in the delivery of Community Supported Living Arrangements are required to establish and maintain a quality assurance program. The quality assurance program must require that providers of service be certified and surveyed using standards that include minimum qualifications and training requirements for staff, financial operating standards, and a consumer grievance process. Monitoring boards are to be established consisting of providers, family members, consumers, and neighbors. Reporting procedures are required to make information available to the public. The health and well being of each recipient of service is to be monitored, and services are to be provided according to an individual support plan. The Medicaid State plan amendment adding community supported living arrangements services must be reviewed by the State Developmental Disabilities Planning Council and by the State Protection & Advocacy System. Public hearings are to be held prior to implementation of the new services.

Maintenance of Effort States providing community supported living arrangements services must maintain current levels of spending for such services to be eligible for participation.

Waiver of Medicaid Requirements Most Medicaid services are required to be comparable throughout the State with respect to the amount, duration and scope of services available to eligible individuals. Under the new limited option, the Secretary is allowed to waive certain Medicaid requirements as needed to carry out the authorized services, and requirements regarding the availability of services statewide.

Minimum Protections The Secretary is required to publish interim regulations by July 1, 1991 and final regulations by October 1, 1992 to protect the health, safety and welfare of individuals receiving community supported living arrangements services. Regulations, through methods other than reliance on State licensure or State quality assurance programs, must include the following assurances:

- persons receiving services must be protected from neglect, physical and sexual abuse and financial exploitation;
- providers of community supported living arrangements services must not hire or otherwise use as caregivers individuals who have been convicted of child or client abuse, neglect or mistreatment, or convicted of a felony involving physical harm, and providers must take all reasonable steps to obtain this information;
- individuals or entities delivering these services must not be "unjustly enriched" as a result of abusive financial arrangements; and
- individuals or entities delivering these services to clients, or relatives of such individuals, may not be the beneficiaries of the life insurance policies purchased by, or on behalf of, such clients.

If providers or services are found out of compliance with the above requirements, the Secretary is to impose a civil money penalty not to exceed $10,000 for each day of its noncompliance.

Limitations of Expenditures $5 million for FY 1991, $12 million for FY 1992, $20 million for FY 1993, $30 million for FY 1994, $35 million for FY 1995 and such sums as provided by Congress thereafter.

Effective The option is effective in approved States on or after July 1, 1991, or 30 days after the publication of interim regulations.

IMPLEMENTATION ACTIVITIES:

- *Contact your State Mental Retardation/Developmental Disabilities director to determine if he/she intends to apply for this*

new Medicaid limited option for Community Supported Living Arrangements (CSLA). Encourage him/her to do so.
- *Monitor the regulatory process by the Health Care Financing Administration and provide public comments at the appropriate time.*
- *Be prepared to contact your Governor and Congressional delegation if your State applies and is denied its application. Medicaid state plan options must be available to all states to expand CSLA.*

OTHER MEDICAID AMENDMENTS

Among the numerous technical amendments to Medicaid law within OBRA '90 are the following which impact Medicaid Home and Community Based Waivers (H-CB), Nursing Home Reform and other Community Services:

- Prohibiting the Secretary of the Department of Health & Human Services from limiting the number of hours of respite services (e.g., 30 hours per month) a State may offer under a Medicaid H-CB Waiver.
- Clarifying Congressional intent that the exclusion of payments for room and board not be applied to payments made for the share of rent or food attributable to staff.
- Requiring that expenditure estimates under Section 1915(d) waivers be adjusted to account for the costs of implementing nursing home reform enacted in OBRA '87.
- Permitting states to adjust their utilization and expenditure estimates to reflect the implementation of the preadmission screening and resident review program (PASARR) under nursing home reform.
- Substituting the phrase "specialized services" for "active treatment" for nursing homes that continue to provide services to people with mental retardation and related conditions and mental illness who are determined through PASARR screening to require "specialized services."
- Codifying the current regulatory definition of Medicaid state optional "rehabilitation services" as "medical or remedial services provided in a facility, home, or other setting, for the maximum reduction of physical or mental disability and restoration of the individual to the best possible functional level."
- Changing the definition of Medicaid state optional "personal care services" to allow such services *outside* of the home for recipients in the State of Minnesota from 1991-1994 and for all Medicaid recipients in the other forty-nine states in 1995 and thereafter.
- Creating a new limited state option for states to develop home and community based services for "frail elderly" persons. Similar in nature to the new CSLA for people with developmental disabilities. Congress appropriated $580 million over five years for this initiative compared to $100 million over five years for CSLA.

SUPPLEMENTAL SECURITY INCOME IMPROVEMENTS

Elimination of Age Limit on Section 1619 Eligibility To be eligible for the Medicaid-only benefit under the section 1619 work incentive provision, individuals must be under 65 years old. The new law eliminates this age limit and is effective November 5, 1990.

Treatment of impairment-related work expenses Impairment-related work expenses will be considered and deducted from income in determining eligibility and re-eligibility for SSI and state supplements. Previously, these expenses were considered only for people who were already eligible. This provision will take effect on March 5, 1991.

Treatment of Royalties and Honoraria as Earned Income Any royalty which is earned in connection with the publication of an individual's work, or any honorarium which is received for services rendered, would be treated as earned income for purposes of SSI eligibility and benefit determination. This would mean that income from these sources would be disregarded to the same extent that income from other types of earnings is disregarded (i.e., the first $65 of monthly earnings plus 50 percent of additional earnings).

Previously, royalties received were considered unearned income under the SSI program unless they were from self-employment in a royalty-related trade or business. Honoraria were also considered unearned income. After the first $20 of unearned income in a month is disregarded, this results in a dollar-for-dollar loss of SSI benefits.

Evaluation of a Child's Disability by Qualified Specialist Present law does not require that a pediatrician or other qualified specialist be involved in the evaluation of a child's disability for purposes of determining SSI eligibility.

The new law requires the Secretary of HHS to make reasonable efforts to ensure that a qualified pediatrician or other specialist in a field of medicine appropriate to the disability of the child evaluate the child's disability. The provision takes effect on May 5, 1991.

Reimbursement for Vocational Rehabilitation Services Under current law, the Secretary of HHS is required to refer individuals with disabilities receiving SSI to State vocational rehabilitation agencies and is authorized to reimburse these agencies for the reasonable and necessary costs of the services from the Social Security Trust Fund. Reimbursement was not allowable for services provided in months for which individuals were not receiving cash benefits but were eligible for Medicaid because they were in section 1619(b) "special status," were in "suspended benefits status," or were receiving Federally administered State supplementary payments but not Federal SSI benefits.

The new provision authorizes reimbursement for vocational rehabilitation services provided in months for which individuals were in "special status" under section 1619(b), were "in suspended benefit status," or were receiving Federally administered State supplemental payments. The provision took effect November 5, 1990 and applies to claims for reimbursement pending on or after that date.

Expansion of Presumptive Eligibility Time Period Under current law, SSA can presume eligibility for up to 3 months while processing applications for SSI on the basis of disability or blindness. The new provision extends the period of presumptive eligibility from 3 to 6 months. The provision is effective on May 5, 1991.

Continuing Disability and Blindness Reviews SSI recipients can participate in the work incentive provision of section 1619 by earning amounts up to the level at which benefits cease ($857 per month for single persons). Even if they are no longer eligible for cash benefits, they can continue to receive Medicaid.

Previously, participants in the work incentive program were subject to continuing disability or blindness review at certain times often more than once a year. The new law limits continuing disability reviews to no more than once every 12 months. The provision became effective on Nov. 5, 1990.

Trusts and Information to Zebley Class While provisions regarding contributions and trusts for SSI beneficiaries did not pass, the law requires the Secretary of Health & Human Services to inform the family of a child who is awarded a retroactive payment as the result of the decision of the Supreme Court in *Sullivan v. Zebley* that the family may be able to place the payment in a trust for the benefit of a child.

Additionally, Conferees recognized how important it is for families to understand how different forms of income, resources and in-kind support are treated under the SSI program and therefore asked that hearings on the issue be held in the 102nd Congress.

OTHER SOCIAL SECURITY IMPROVEMENTS

Telephone Service Centers Demonstration Projects OBRA '90 authorized three demonstration projects in not less than three telephone service centers requiring that a written receipt be provided to the callers of SSA's toll-free telephone number who request information about potential or current eligibility or entitlement to benefits. The project must begin no later than May 5, 1991.

Social Security Notices The law requires that Social Security notices on or after July 1, 1991, be written in clear and simple language, and in the case of notices from field offices, contain the address and telephone number of the local office which services the individual. If the notice is not produced in the field office, it would have to contain the address of the field office serving the individual and a telephone number through which that office can be reached.

Telephone Access The law calls for the restoration of telephone access to local Social Security offices to the level generally available on September 30, 1989, and requires the Secretary to request the publication of telephone numbers and addresses of local offices which maintain direct telephone access by May 5, 1991. SSA will report by January 1993, on the impact of the provision and a plan to use new technologies to enhance access to SSA, including local offices. The General Accounting Office will report on the level of telephone access to local offices not later than March 5, 1991 and June 5, 1991.

Improvement in Earnings and Benefit Statements Beginning October 1, 1999, SSA will send each year to all workers covered under Social Security a statement concerning earnings and potential benefits. Current law requires statements to be sent every two years beginning October 1999.

Trial Work Period During Rolling 5-year Period for All Disabled Beneficiaries This provision provides that a disabled beneficiary will exhaust a 9-month trial work period if he/she performs services in 9 months in a rolling 60-month period, i.e., within any period of 60 consecutive months. The provision repeals the provision which precludes a re-entitled disabled worker from being eligible for a Trial Work Period.

Continuation of Benefits on Account of Participation in a Non-State Vocational Rehabilitation (VR) Program This provision extends to SSDI and SSI beneficiaries who medically recover while participating in an approved non-State VR program the same benefit continuation rights as those who medically recover while participating in a State VR program until completion of the rehabilitation program.

Auxiliary Benefits Codifies current SSA policy that provides for suspension of benefits to auxiliary beneficiaries when the disabled worker's benefits are suspended because he/she is engaging is substantial gainful activity during the 36-month "extended period of eligibility" that follows the trial work period.

Vocational Rehabilitation Demonstration Projects Requires the Secretary to conduct demonstration projects, which would run for 3 years in at least three states, to assess the advantages and disadvantages of permitting disabled beneficiaries to select a qualified rehabilitation provider, either public or private, to furnish them with services enabling them to engage in substantial gainful activity and to leave the disability rolls.

Recovery of OASDI Overpayments by Means of Reductions in Tax Refunds Permits SSA to recover overpayments from former beneficiaries by means of offsetting income tax refunds under the same authority applicable to other Federal programs.

Notice Requirements The law requires SSA to use clear and simple language in all of its Social Security and SSI notices. SSA must include the local office phone number and address in notices generated by local offices and in notices generated by SSA central offices, must include the same information regarding the local office serving the persons. This provision is effective July 1, 1991.

IMPLEMENTATION ACTIVITIES:

- *The OBRA '90 contains numerous other Social Security and SSI provisions. Please contact Jenifer Simpson at (SSA) USA-5UCP or (202) 842-1266 if you would like a copy of the Social Security Administration's Legislative Bulletin which covers all OBRA '90 provisions.*

CHILD CARE

Child Care and Development Block Grant (P.L. 101-508) OBRA '90 authorized a new child care block grant to increase the availability, affordability, and quality of child care. The provision provides financial assistance for low-income, working families to help them find and afford quality child care services for their children. It also contains a provision to enhance the quality and increase the supply of child care available to all parents, including those who receive no financial assistance under the block grant program.

The new Law authorizes $750 million for fiscal year 1991, $825 million for fiscal year 1992 and $925 million for 1993.

Child Care Services and Activities Each State must use 75 percent of block grant funds for direct assistance to parents for child care services, to increase the supply and to improve the quality of child care. Block grant funds may only be used by the states for child care services and for activities which directly improve the availability and quality of care for families assisted under the Act.

Twenty-five percent of block grant funds are reserved for quality improvements, early childhood education and latchkey programs. States must use no less than 20 percent of the reserved funds for quality improvement activities. These may include: grants or loans to help providers meet state or local standards; support for resource and referral programs; activities to improve enforcement of state standards and licensing requirements; training and technical assistance; and improvement of salaries for child care providers.

Of the 25 percent of the block grant funds reserved by each State, not less than 75 percent of this reserve shall be allocated to early childhood development and before- and afterschool child care activities.

A State may assign responsibility for the administration of early childhood development and latchkey programs to an agency other than the lead agency, such as an agency that has experience in administration of existing education or preschool programs.

Eligibility Eligible families for child care are those who earn less than 75 percent of the state median income and who have children under age 13. The amount would be based on a sliding fee scale established by the State. Providers are to receive payment at rates which would ensure equal access to services comparable to those provided to children whose care is not publicly subsidized.

Parental Rights Parents will have complete discretion to choose from a wide range of child care arrangements, including care by relatives, churches, synagogues, family providers, centers, schools, and employers. States must offer eligible parents certificates to help to pay for child care of their choice.

Parental choice and involvement are further enhanced through provisions for unlimited parental access to the child during the day and at the child care setting. States must offer consumer education to parents to help them select child care, establish parental complaint procedures and maintain records of substantial parental complaints.

State Plan To receive funds, a State must submit a plan that includes: designation of a lead agency; local consultation regarding development of the plan; coordination with existing programs; use of funds for child care services, including early childhood education and before and after school care, and for activities related to quality and availability; supplement not supplant language; priority for very low income children and children with special needs; and use of a sliding fee scale.

Health and Safety Requirements The State plan must describe minimum health and safety requirements established by the State for all providers and ensure compliance with these requirements. These health and safety requirements include the prevention and control of infectious diseases, premises safety, and minimum health and safety training requirements appropriate to the provider setting.

Licensing and Reporting Requirements All eligible providers will be licensed, regulated, or registered prior to payment and must comply with applicable state and local licensing and regulatory requirements.

The state will conduct a one-time review of licensing and regulatory requirements.

States must report annually to the Secretary of Health and Human Services on such matters as the use of funds, number of children in care, participating providers, caregiver salaries, public-private child care partnership activities, actions to improve availability and quality of care, and state standards.

States that lower standards must provide rationale for this action.

IMPLEMENTATION ACTIVITIES:

- *Contact your Governor's Office to determine the name of the State agency and a contact person in that agency who will be responsible for developing and implementing the Child Care and Development Block Grant.*
- *Advocate for a planning process which includes an advisory committee consisting of families and providers including families with a child with disabilities. This committee should also comment on State standards (current or future) to be sure they include relevant items for children with disabilities.*
- *Encourage the State to conduct public hearings on the plan.*
- *Advocate for the plan to include training and technical assistance to generic day care providers to provide "reasonable accommodation" for the inclusion of children with disabilities, as required by the Americans With Disabilities Act.*
- *Disseminate information to families with low incomes about the availability of the new law as well as the new earned income tax credits described below.*

NEW ENTITLEMENT FOR CHILD CARE Federal matching is currently available to States on an entitlement basis to provide child care for AFDC parents who are participating in the JOBS program, and to provide child care for a period of 12 months after the family loses eligibility for AFDC as a result of increased hours of or increased income from, employment.

Under the new law, States will receive a total of $500 million per year ($1.5 billion over five years) beginning in fiscal year 1991 to provide child care to families who need such care in order to work and would otherwise be at risk of becoming dependent on AFDC. Child care providers receiving funds would have to be licensed, regulated, or registered, except that no requirements would apply to care provided solely to family members.

In addition $50 million per year, beginning in fiscal year 1992, has been authorized (but not yet appropriated) to improve State standards, monitor compliance with standards, and provide training to providers. Half of these funds would be used for training.

TAX CREDITS FOR LOW-INCOME FAMILIES

Present Law Certain individuals who maintain a home for one or more children are allowed an advance refundable tax credit based on the taxpayer's earned income. In 1990, the Earned Income Tax Credit is equal to 14 percent of the first $6,810 of earned income. The credit is phased out at a rate of 10 percent of the amount of income eligible for the credit increase with inflation. The Earned Income Tax Credit is not adjusted by reason of family size or the fact that a child is under age one.

Basic Credit Beginning in 1991 the Earned Income Tax Credit increases to a projected maximum in 1994 of $1,852 for a family with one child and $2,013 for a family with two or more children, compared with $1,127 under current law for all family sizes.

Supplemental Credit for Newborns The law provides an additional credit to low-income families with a child under age one, beginning in 1991. The projected maximum credit for newborns would be $355 in 1991. Eligible families could claim this credit or the dependent care tax credit, but not both. This credit is available for taxable years beginning after December 31, 1991.

Earned Income Tax Credit for Health Insurance Premiums — Present Law Expenses for medical care, including health insurance premiums, are deductible to taxpayers who itemize deductions to the extent the expenses exceed 7.5 percent of adjusted gross income (AGI). Health insurance provided by an employer is excludable from gross income. Self-employed individuals are entitled to deduct only 25 percent of the amount of health insurance expenditures. Present law does not provide a credit for the cost of health insurance.

The new law creates a health tax credit for out-of-pocket costs for health insurance premiums paid for with after-tax dollars including the health insurance premiums of children. The health tax credit is refundable regardless of one's tax contributions but does not cover copayments, deductibles or out-of-pocket medical expenses. The maximum amount of the tax credit is calculated based on a percentage of earned income (up to the maximum amount of creditable earned income in effect for the Earned Income Tax Credit.) For 1991, the maximum health credit is projected to be $426. The amount of expenses available to be considered by the taxpayer for purposes of the medical expense deduction is reduced dollar-for-dollar by the amount of the allowable tax credit.

LIMITATION IN CHARITABLE DEDUCTIONS FOR HIGH INCOME Individuals with adjusted gross incomes of $100,000 or more have a 3 percent floor of their combined deductions for state and local taxes, mortgage interest payment, and charitable contributions. This only applies to income above $100,000. If a person or couple have an adjusted gross income of $150,000, they will not be able to claim the first $1,500 of deductions (3 percent of $50,000) of income that is above the baseline figure of $100,000.

The baseline figure of $100,000 is "indexed to inflation."

GIFTS OF APPRECIATED PROPERTY For 1991, people will be able to get the full market value deduction for gifts of books, manuscripts, works of art and other "tangible property" but not including stock and real estate.

IMPLEMENTATION ACTIVITIES:

- *This one year tax deduction for the full market value of books, manuscripts, works of art and other "tangible property", except stocks and real estate, can be very useful to local LCP affiliates and other nonprofit corporations in soliciting donor gifts either for program use or for resale in a fundraising auction, drawing or other special event.*

ADA TAX CREDIT FOR SMALL BUSINESS An eligible small business may elect to take a general business credit of up to $5,000 annually for eligible access expenditures to comply with the requirements of the ADA. The amount which may be taken as a credit is 50 percent of the amount exceeding $250 but less than $10,250 per tax year. The credit is effective as of November 5, 1990.

Eligible Small Business The term "eligible small business" means either a business with gross receipts of $1 million for the taxable year or 30 or fewer full-time (30 hours a week for 20 or more weeks a year) employees.

Eligible Access Expenditure The term "eligible access expenditure" means reasonable expenditures to comply with the ADA.

Expenditures include:

a) removing architectural, communication, physical, or transportation barriers which prevent a business from being accessible to, or usable by, individuals with disabilities;
b) providing qualified interpreters or other effective methods of making aurally delivered materials available to individuals with hearing impairments;
c) providing qualified readers, taped texts, and other effective methods of making visually delivered materials available to individuals with visual impairments;
d) acquiring or modifying equipment or devices for individuals with disabilities; or
e) providing other similar services, modifications, materials or equipment.

New Construction Facilities first placed in service after November 5, 1990 are not covered by the Act.

Standards The "eligible access expenditures" must concur with the standards of the Architectural and Transportation Barriers Compliance Board and regulations set forth by the Secretary.

Reduction in the allowable tax credit for Architectural and Transportation Barrier Removal Expenses This current tax credit for the removal of architectural and transportation barriers to individuals with disabilities and elderly individuals is reduced from $35,000 to $15,000.

IMPLEMENTATION ACTIVITIES:

- *Develop a fact sheet on the ADA tax credit for small businesses. Since most employers are small businesses, this credit is a great asset in securing jobs for people with disabilities under the provisions of the ADA.*
- *Disseminate this information to persons with disabilities, family members, board members, local businesses and other interested parties.*
- *Link the ADA tax credit with the reauthorization of the Targeted Job Tax Credit as a marketing strategy to develop collaborative relationships with small businesses by assisting them in the employment of people with disabilities.*

TARGETED JOB TAX CREDIT OBRA '90 extended for one year the Targeted Job Tax Credit (TJTC) to October 1991. TJTC is a critically important incentive for encouraging employers to hire people with disabilities and other eligible persons. Under TJTC, employers can claim a tax credit of 40 percent of the first $6,000 of qualified wages per eligible employee, with a maximum credit of $2,400 per employee during the first year of employment. Because the program has previously received numerous annual extensions which serve only to erode employer confidence, it is expected that both the House and Senate will seek a three-year extension of the program in the 102nd Congress.

AUGUSTUS F. HAWKINS HUMAN SERVICES REAUTHORIZATION ACT OF 1990 (P.L. 101-501) This legislation, more commonly referred to as the "HEAD START" reauthorization bill, was signed by President Bush on November 3, 1990. In addition to reauthorizing the Head Start program and authorizing increased funding from $2.39 billion in FY 1991 (which was appropriated) to reach full funding of $7.6 billion in FY 1994, this legislation reauthorized several other programs and created several new ones, all of which have potential impact on children with disabilities and their families. Within the Head Start Reauthorization are the following:

• Funding Set Aside for Quality Enhancement.

Each year in which the appropriations exceed the prior year's appropriation, adjusted for inflation, the Secretary of Health & Human Services (HHS) is required to set aside a portion of the increased funds to improve Head Start program quality. In FY 1991 the set-aside is ten percent of appropriated funds and goes to twenty-five percent in subsequent years. At least fifty percent of the set-aside funds must be used to increase salaries and/or benefits for Head Start staff for improving staff recruitment and retention. The other fifty percent of the set-aside may be used for any of the following: (a) to pay transportation costs for Head Start students; (b) to hire additional staff; (c) to purchase non-employee insurance to maintain or expand Head Start services; (d) to supplement other funds provided for staff training; and (e) to make non-structural and minor structural changes and to acquire and install equipment needed to expand the availability of quality of Head Start programs.

The law requires the Secretary of HHS to distribute eighty percent of the set-aside funds in FY 1991 and FY 1992 to states based on a formula basis and to local grantees based on child count. The remaining twenty percent is for use at the Secretary's discretion. In subsequent years, all of the set aside funds are to be distributed to the States on the current Head Start formula; however, local grantee distribution is at the Secretary's discretion.

• Full-Day, Full-Year Services.

The law clarifies that services may be provided to eligible children on a full-day basis and throughout the year.

• Parent-Child Centers.

The law creates a new early childhood intervention program within Head Start agencies called "Parent Child Centers." The purpose of the Centers is to enhance the development of children under age 3 (minimum age for Head Start) by providing social, health and educational services to low-income families with children under three. The program may be center-based, home-based, or a combination, but may not detract from services funded to core Head Start enrollees. In FY 1991 the set-aside for this new program is $30 million which increases to $33.7 million in FY 1994.

• Head Start Transition Project.

This new initiative sets aside $20 million for each fiscal year (1991-1994) for grants to Head Start agencies to develop and operate programs to assist low-income elementary school students from Kindergarten through Grade 3 with priority going to children entering their first year of school. The focus of the programs is to assist families obtain such supportive services as health care, immunization and mental health services, and nutrition and social services etc.

• Studies/Report.

The law requires a number of longitudinal studies and status reports to be provided to Congress on the Head Start program.

Within P.L. 101-501 is the Claude Pepper Young Americans Act of 1990. This legislation creates in statute the Administration on Children, Youth and Families within the Department of Health & Human Services. The law also establishes an eighteen-member federal Council on Children, Youth and Families to review and evaluate federal policies and programs affecting children and youth. The Council is required to report annually to the President, Health & Human Services Secretary, Commissioner of Adults, Children, Youth & Families and to Congress with funding and recommendations regarding ways to reduce duplication and enhance coordination of services. This legislation also creates:

• National Center of Family Resources and Support Programs with an authorization level of $2.3 million in FY 1991. This center is to serve as a national information and data clearinghouse and as a source of training, technical assistance, and material development for family resource and support programs.

• White House Conference on Children, Youth and Families by requiring the President to convene such a conference in 1993 to develop recommendations for further action in the field.

Other programs reauthorized in P.L. 101-501 are: The Community Food and Nutrition Program; The Community Services Block Grant Program (CSBG); Follow Through; The Low-Income Home Energy Assistance Program; Comprehensive Child Development Centers and several others.

IMPLEMENTATION ACTIVITIES:

• *Obtain a copy of P.L. 101-501 from your U.S. Senator or Congressperson. The Head Start program is one of President Bush's top domestic priorities and is expected to receive significant increases in appropriations.*

• *Contact your local and state Head Start agencies to advocate for the inclusion of funding for training and technical assistance in meeting the needs of children with disabilities and their families as well as funding for structural changes and equipment to accommodate youngsters with disabilities in*

their programs as part of their plans for using set-aside funds to improve program quality. ***Head Start is required to have an enrollment of at least ten percent of children with disabilities.***

- *Contact your local and state Head Start agencies to encourage their application for new Parent-Child Center funding and to advocate for the inclusion of services and supports (in coordination with the State's Interagency Coordinating Council planning for implementation of Part H of P.L. 99-457), for infants and toddlers with disabilities and their families.*
- *Continue to work with your local and state Head Start agencies in the expansion and enhancement of their programs and the inclusion of quality services for children with disabilities and their families.*

DISAPPOINTMENTS OF THE 101ST CONGRESS

CIVIL RIGHTS ACT OF 1990 The Civil Rights Act of 1990 won approval in the U.S. House and Senate in 1990; however, the President vetoed the bill. Congress failed to override the Presidential veto by one vote.

The legislation is designed to restore civil rights employment protections under the 1964 Civil Rights Act and Section 1981 of the 1866 Civil Rights law, which were weakened by several Supreme Court decisions issued in 1989. The 1990 legislation would also strengthen Title VII of the 1964 Act by providing both compensatory and punitive damages for those who have been intentionally discriminated against on the basis of not only race but for reasons of gender, religion, ethnic origins or disability as well.

The 1990 bill also had implications under the Americans with Disabilities Act. To ensure equal treatment in the resolution of discrimination cases against all protected "classes" of individuals, the ADA stipulates that persons who have been discriminated against on the basis of disability shall have all the rights and remedies available to them as found in the 1990 Civil Rights Act. The civil rights community will seek to gain passage of similar legislation in the 102nd Congress.

FAMILY MEDICAL LEAVE ACT (FMLA) In July 1990, the 101st Congress sustained President Bush's veto of a bill that would require employers to grant unpaid leave to workers caring for newborn children or sick relatives. The House vote, 232-195, fell 54 short of the two-thirds necessary to override the veto.

This legislation would have protected jobs for workers who take up to 12 weeks of unpaid leave to care for a newborn, adopted or ill child. It also would have covered time off for personal medical emergencies, including caring for family members.

MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT OF 1989 Although Senator Lloyd Bentsen (TX), Chairman of the Senate Finance Committee, promised Senator John Chafee (RI), sponsor of S.384, the Medicaid Home and Community Quality Services Act of 1989, that the Committee would mark up the bill during 1990. As the summer came to an end, it became increasingly apparent that this legislation would only be considered—if at all—during the omnibus budget reconciliation process in the fall.

S. 384, a vastly different piece of legislation from Senator's Chafee's earlier bills, and one strongly endorsed by UCPA with two technical amendments, proposed to freeze the amount of federal Medicaid matching funds going to States for Medicaid ICF/MR facilities of greater than fifteen persons at the then current level one year after the bill would have been enacted. In exchange, the federal funds that would have been spent on growth in the "large" ICF/MR program in subsequent years would have been redirected to a five year phase-in State/federal Medicaid entitlement for persons with severe disabilities and would have consisted of family support services; community living services of no more than three times average family census size; specialized vocational services including long-term supported employment funding; independent case management services; and a comprehensive state quality assurance program.

Although endorsed by over twenty-five national organizations, S. 384 was primarily opposed by parents of children in large ICF/MR facilities and state employee unions. During September of 1990, concerns about the cost of implementations became the policy issue. That is, the funds for the phased-in five year mandated entitlement would all have to be new federal funds. The estimates for this expenditure ranged from $1.0 billion over five years to billions over 5 years, neither of which were palatable in a political climate of alleged deficit reduction.

As a result of these issues, advocates worked with the staffs of Senators Chafee and Bentsen to carve out a new initiative consistent with current best practice and values in the field. After much intense debate and redrafting, the Senate Finance Committee was willing to expend only $100 million over five years which resulted in the new limited State option for Community Supported Living Arrangements (see p. 7 of this issue of *WfW*).

ACCESS TO HEALTH CARE Congress repealed the Catastrophic Health Insurance Act of 1988 through Public Law 101-234 under intense resistance from seniors who resented the precedent that improvements in the Medicare benefits would be financed entirely by higher premiums on persons over 65. Although the Catastrophic Health Insurance Act would have filled certain important gaps in Medicare by: (1) expanding hospital and skilled nursing facility benefits; (2) setting a maximum on out-of-pocket expenses; and (3) creating a new outpatient prescription drug benefit, long term home care would have remained uncovered by Medicare. To remedy this problem and to create universal access to health care, Congress created the Pepper Commission to develop a workable plan to address the rapidly growing crisis in health and long term care.

The Pepper Commission (also known as the U.S. Bipartisan Commission on Comprehensive Health Care) developed recommendations for building universal coverage by reforming and extending the job-based private health insurance system and creating an alternative public plan. The job-based health insurance system would consist

of: (1) a "pay or play" employer mandate with tax credits/subsidies for small employers; (2) a federally specified minimum benefit package for preventive and primary care as well as other physician and hospital care (but not for drugs, rehabilitation, durable medical equipment or extended psychiatric care); (3) sliding scale premiums; (4) cost-sharing requirements with limits and managed care for cost containment; and (5) national practice guidelines. In addition, the Pepper Commission recommended health insurance market reforms which would prohibit medical underwriting, rating, and marketing practices by private health insurers which are undermining the integrity of the small group market. The public system for persons who are poor and unemployed and those not in job-based insurance plans would consist of: (1) replacing Medicaid through a system entirely federally funded, severed from the welfare system, with uniform eligibility requirements and benefits among the states, and Medicare reimbursement levels; and (2) expanding public coverage for certain vulnerable groups, such as persons with disabilities, who may need case management for coordinating social and health services. As evidence that the Pepper Commission went as far as it could go in reflecting a current consensus in Congress, the bipartisan commission split 8-7 on its recommendations for phasing in a universal right to health care.

While many in Congress continue to proclaim that there is little support for a fundamental change in health care financing, in the United States health care expenditures increased by $50 billion each year while 37 million persons remain uninsured. It is inescapable that Congress will notice that private health insurance companies pay for less than one-third of all health care expenditures, while the Federal and State governments pay for over 40 percent of the aggregate cost of health care (another third is paid out-of-pocket by consumers). As Congress seeks to balance the problem of uncontrolled health care costs on the one hand, and barriers to access on the other, the American public has yet to recognize that the right of all Americans to comprehensive health care is ultimately at stake.

Outlook for the 102nd Congress

by Allan I. Bergman

The 102nd Session of Congress is scheduled to convene formally on Thursday January 3, 1991. President Bush will deliver his State Of The Union Address on January 29th, and present his Fiscal Year 1992 budget on February 4th, 1991. As a result of the 1990 election and the retirement of several senior Members of Congress, the membership of a number of Senate and House Committees will be changing. Democratic and Republican Senate and House Members recently elected key leadership for the 102nd Congress with several significant changes.

International issues, including the recent resignation of the Soviet Union's Foreign Minister, Edvard Shevardenadze, the increasing tensions between the United States and Iraq over the Iraqi invasion of Kuwait and the potential for major war, will dominate the early business of the Congress. On the domestic front, the continuing "lull" in the economy will be declared a recession and debate concerning lowering interest rates, statistics reflecting increasing unemployment, stringent standards for credit, the potential insolvency of many commercial banks and the need for the government (taxpayers) to bail out the Federal Deposition Insurance Corporation (as we are doing for the Savings & Loan institutions) will all get substantial attention from Congress.

In spite of all of these major policy issues which will capture the media during 1991 and 1992, Congress will engage in public policy debate and make decisions impacting the lives of American citizens with disabilities and their families for the remainder of the decade. Most of the domestic policy agenda items, however, will be discussed within the context of the budget deficit agreements achieved in the Omnibus Budget Reconciliation Act of 1990 (OBRA '90, P.L. 101-508, see *Word From Washington*, September/October, 1990).

- **FY 1992 Budget and Appropriations Process.**
  The FY 1992 budget and appropriations figures are contained in OBRA '90. Most federal programs impacting children and adults with disabilities and their families (other than Social Security, Medicaid and Medicare) fall into the category of "domestic discretionary." The total funding for domestic discretionary programs can increase only by an annual cost-of-living figure, estimated at five percent. At a practical level, this means that the House and Senate Budget Committees have no responsibilities for the FY '1992 budget figures and, more importantly, that the Appropriations Committees have very little ability to make changes. This is so because the new budget process "triggers" a mini-sequestration on actual and projected *expenditures* rather than on the projected deficit. Moreover, the sequestration process is under the control of the Office of Management and Budget. Therefore if, for example, the Appropriations Committee with jurisdiction for funding Part H of P.L. 99-457 (early intervention for infants, toddlers and their families) wishes to increase the appropriations more than the five percent cost-of-living amount, the Committee literally must "take" the funds from another program under its jurisdiction. The Committee ***cannot exceed the five percent total CAP*** **even if it wishes to propose an offsetting source of new revenue.** Because of the redefined budget process, we do not expect to see a budget reconciliation bill since it will be unnecessary. The lack of an OBRA '91 may impact many other areas, including Medicaid expansions, since all such changes have occurred in similar bills since 1980.
- **Reauthorization of the Rehabilitation Act.**
  The Rehabilitation Act will expire on September 30, 1991. Both the Senate Subcommittee on Disability Policy and the House Subcommittee on Select Education expect to hold hearings on this legislation in early spring of 1991. This legislation governs the basic state and federal vocational rehabilitation program in each State,

contains the authority for the National Institute on Disability and Rehabilitation Research, and contains the authority for independent living centers and supported employment. Last authorized in 1986, Congress amended the law to make rehabilitation engineering part of the vocational rehabilitation process and to create supported employment as Title VI (c). During the past five years, people with the most severe disabilities have continued to prove that, with appropriate supports, no one who wants to work is any longer "non-feasible" for employment. UCPA and other national disability organizations have begun discussions regarding the need for major reformulation of the law consistent with the value, best practices and increased empowerment of persons with disabilities to take control of their own lives.

There is also discussion of creating a new Title VIII in the Act, for Personal Assistance Services, in which funds would be authorized for personal assistance from attendants, interpreters or readers to individuals meeting disability and income eligibility standards.

•Reauthorization of Part H, P.L. 99-457.

Part H of P.L. 99-457, early intervention for infants and toddlers with disabilities and their families, will expire on September 30, 1991. The Senate Subcommittee on Disability Policy and the House Subcommittee on Select Education intend to hold hearings in the spring of 1991 on Part H. Although most States have expended significant energy in moving toward a 1991-1992 implementation of a statewide entitlement, few states appear capable of making the resource commitments. The reauthorization process will focus on a number of technical/semantic changes, whether a less intense program should be offered to infants and toddlers labeled "at risk," Medicaid financing issues and future federal funding. Early indications from the Hill suggest that the final implementation timetable will not be changed so that those States which are prepared are rewarded; however, States which cannot make the fifth year commitment may be allowed to continue to apply for and receive federal funds to continue planning.

- **Reauthorization of the Children With Disabilities Temporary Care Act.**

This legislation, just reauthorized for two years in 1989 (see this issue of *Word From Washington*, page --) will be heard by the Senate Select Subcommittee on Children, Youth and Families and the House Subcommittee on Select Education. In view of the continuing soundness of the many small pilot projects throughout the country funded by this legislation, there is increasing interest to redirect the program from a temporary one to a permanent one. In the latter case, UCPA will urge the expansion of the program from respite care and crisis nurseries to a more comprehensive program of family support for families with a child with a disability. Early discussions with Congressional and Executive agency staff indicate interest in an expansion and reformulation of the program during reauthorization.

- **Medicaid Reform.**

The 1991 agenda for Medicaid Reform will be significantly different from prior legislation. Because of the adamant opposition of Senator Lloyd Bentsen (TX), Chairman of the Senate Finance Committee, and Representative Henry Waxman (CA) to the imposition of any cap, freeze or limit on federal Medicaid expenditures for the ICFs/MR program (see this issue of *Word From Washington*, page --), the strong resistance of the National Governor's Association to new Medicaid mandates, the budget dilemma and the expectation of no budget reconciliation bill in 1991, major Medicaid activities probably will not occur before the summer and fall of 1992. Disability organizations may, however, work in concert with the National Governor's Association to expand the new Medicaid limited state option for Community Supported Living Arrangements (CSLA) from two to eight states to an option for all fifty states. Some disability advocates are suggesting a new, phased-in mandated program building upon CSLA, adding supported employment services (long-term), independent service coordination (case management) services and a comprehensive quality assurance component.

- **Civil Rights Act of 1991.**

Leading proponents of the Civil Rights Act of 1990 will reintroduce early in 1991 the legislation passed both by the Senate and the House in 1990, with the intent of achieving a two-thirds majority to override an anticipated veto by President Bush.

- **Family Medicaid Leave Act (FMLA).**

House sponsors plan to reintroduce the FMLA on January 3, 1991, the first day of business for the 102nd Congress. The bill will be identical to the legislation that was passed by a majority bi-partisan effort in May of 1990. This legislation provides for up to twelve weeks of unpaid leave annually to workers who need time to care for a newborn or newly adopted child, for the serious health condition (e.g., disability) of a child, spouse or parent, or to recover from their own serious health conditions. Leaders in the Senate plan to introduce a similar bill on January 23 with two exceptions: the Senate bill equalizes leave rights for federal and private sector employees, and it does not contain an exemption for "key employees."

- **Health Care and Insurance.**

A number of bills are expected to be introduced throughout 1991 in response to the report of the Pepper Commission and the continuing concern and crisis in health care for all Americans including Americans with disabilities. The 102nd Congress also will consider the Kennedy-Waxman Basic Health Benefits bill, new proposals by the Health Insurance Association of America to reform the health insurance system, and a growing interest in a single payer system, as currently exists in Canada. With the defeat of Representative Douglas Walgren's (PA) bid for reelection to his seventh term and his post as the Chairman of the House Subcommittee on Commerce, Consumer Protection, and Competitiveness, was providing leadership on access to health insurance for persons with disabilities and their families, disability advocates will need to cultivate new advocates in Congress. More importantly, UCPA and the disability community will be working to assure inclusion of our issues in the broader health care debates.