

SEC. 2. 41 THORIZATIONS OF APPROPRIATIONS.

The Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6000 et seq.) is amended—

(1) in section 130, by striking "\$50,250,000" and all that follows and inserting "such sums as may be necessary for fiscal years 1988 through 1990.";

(2) in section 143, by striking "\$13,750,000" and all that follows in the first sentence and inserting "such sums as may be necessary for fiscal years 1988 through 1990.";

(3) in section 154, by striking "\$9,000,000" and all that follows and inserting "such sums as may be necessary for fiscal years 1988 through 1990."; and

(4) in section 163, by striking "\$2,700,000" and all that follows and inserting "such sums as may be necessary for fiscal years 1988 through 1990."

SEC 3. ADDITION OF FAMILY SUPPORT SERVICES

TO LIST OF PRIORITY SERVICES WITH RESPECT TO PERSONS WITH DEVELOPMENTAL DISABILITIES.

(a) IN GENERAL.—Section 102(11)(C) of the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6001(11)(C)) is amended—

(1) by striking "and";

(2) by striking the period and inserting a comma; and

(3) by adding at the end, "and family support services."

(b) DEFINITION OF FAMILY SUPPORT SERVICES.—Section 102(11) of the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6001(11)) is amended by adding at the end the following new subparagraph:

"(f) The term 'family support services' means services designed—

(i) to strengthen the role of the family as the primary care-giver;

(ii) to prevent out-of-home placement;

(iii) to reunite families with family members who have been placed out of the home; and

(iv) to maintain family unity."

(c) CONFORMING AMENDMENT.—Section 102(11)(D) of the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6001(11)(D)) is amended by striking "family support services."

SEC. 4. REVISION OF DEFINITION OF SUPPORTED EMPLOYMENT OF PERSONS WITH DEVELOPMENTAL DISABILITIES.

Section 102(11)(F) of the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6001(11)(F)) is amended—

(1) by striking "paid" the first place it appears and inserting "competitive"; and

(2) by amending clause (1) to read as follows:

"(I) is for persons—

(I) with developmental disabilities who are members of groups for which competitive employment, has not historically occurred, or

(II) for whom competitive employment, has been interrupted or intermittent, because of developmental disability,

who, because of their disabilities, need intensive ongoing support to perform in a work setting."

SEC. 5. REQUIREMENT OF PROVISION OF NOT LESS THAN ONE PRIORITY SERVICE TO PERSONS WITH DEVELOPMENTAL DISABILITIES.

(a) IN GENERAL.—Section 122(b)(4)(B) of the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6022(b)(4)(B)) is amended to read as follows:

"(B) The plan must provide for not less than one of the five priority services. The plan may, in the discretion of the State, provide for more than one priority service,

or for one or more services described in section 102(11)(A)(ii), or both."

(b) STRIKING OF CERTAIN REQUIREMENT WITH RESPECT TO EXPENDITURES OF PAYMENTS.—Section 122(b)(4) of the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6022(b)(4)) is amended—

(1) by striking subparagraph (C); and

(2) by redesignating subparagraphs (D), (E), and (F) as subparagraphs (C), (D), and (E), respectively.

(c) CERTAIN REQUIREMENT WITH RESPECT TO EXPENDITURES OF PAYMENTS.—Section 122(b)(4)(D)(i) of the Developmental Disabilities Assistance and Bill of Rights Act (as redesignated in subsection (b)(2)) is amended by striking "service activities in the priority services." and inserting "services described in subparagraph (B)."

SEC. 6. REVISION IN CATEGORIES OF REPRESENTATIVES ON STATE PLANNING COUNCIL.

Section 124(a)(3)(B)(ii) of the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6024 (a)(3)(B)(ii)) is amended by inserting "or previously institutionalized" after "institutionalized."

SEC 7. REPORTS BY STATES WITH RESPECT TO SERVICES PROVIDED TO PERSONS WITH DEVELOPMENTAL DISABILITIES.

The Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6000 et seq.) is amended by adding at the end the following new part:

"PART F—DEVELOPMENTAL DISABILITIES STATUS REPORT

"REQUIREMENT OF CERTAIN ASSURANCES WITH RESPECT TO REPORT

Sec. 171. (a) For each of the fiscal years 1988 through 1990, the State plan required by section 122 must contain or be supported by assurances satisfactory to the Secretary

that, not later than September 30, 1990, the State will submit to the Secretary a report containing a comprehensive description of—

(1) the eligibility, standards established by the State for the receipt of services by persons with developmental disabilities;

(2) a description of the services provided by the State to individuals with developmental disabilities;

(3) the extent to which the State is meeting the needs of persons with developmental disabilities;

(4) the extent to which the State is carrying out the purposes of this title, including a description of the manner in which the State has construed, and is construing the term 'developmental disability';

(5) the recommendations of the State for meeting the needs of all persons in the State with developmental disabilities, including recommendations with respect to appropriate initiatives by the State and by the Federal Government; and

(6) with respect to the matters referred to in paragraphs (1) through (5), the views of persons in the State with developmental disabilities and the views of persons in the State who are advocates for persons with developmental disabilities

(b) For each of the fiscal years 1988 through 1990, the State plan required in section 122 must contain or be supported by assurances satisfactory to the Secretary that, in preparing the report required in subsection (a), the State will—

(1) conduct a study for the purpose of obtaining the information required in subsection (a)(6) and will, in conducting such study, survey a representative sample of persons in the State with developmental disabilities and a representative sample of persons in the State who are advocates for persons with developmental disabilities; and,

DEVELOPMENTAL DISABILITIES ASSISTANCE EXTENSION ACT OF 1987

Mr. BRUCE. Mr. Speaker, I move to suspend the rules and pass the bill (H.R. 1871) to amend the Developmental Disabilities Assistance and Bill of Rights Act to extend the programs established in such act, and for other purposes, as amended.

The Clerk read as follows: H.R. 1871

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE

This Act may be cited as the "Developmental Disabilities Assistance Extension Act of 1987".

(a) IN GENERAL.—Section 122(b)(4)(B) of the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6022(b)(4)(B)) is amended to read as follows:

"(B) The plan must provide for not less than one of the five priority services. The plan may, in the discretion of the State, provide for more than one priority service,

or for one or more services described in section 102(11)(A)(ii), or both."

"(2) provide public notice with respect to the development of the report and such opportunities as may be necessary to provide interested persons an opportunity to present comments and recommendations with respect to the report.

REQUIREMENT OF SUBMISSION OF STATEMENT OF PROGRESS WITH RESPECT TO REPORT

SEC. 172. For each of the fiscal years 1989 and 1990, the State plan required in section 122 must contain a statement of the progress made by the State with respect to completing the report required in section 171.

The amendments made by this Act shall take effect October 1, 1987, or upon the date of the enactment of this Act, whichever occurs later.

The SPEAKER pro tempore. Is a second demanded?

Mr. LENT. Mr. Speaker, I demand a second.

The SPEAKER pro tempore. Without objection, a second will be considered as ordered.

There was no objection.

The SPEAKER pro tempore. The gentleman from Illinois [Mr. BRUCE] will be recognized for 20 minutes and the gentleman from New York [Mr. LENT] will be recognized for 20 minutes.

The Chair recognizes the gentleman from Illinois [Mr. BRUCE].

Mr. BRUCE. Mr. Speaker, I yield myself such time as I may consume.

Mr. Speaker, the legislation before us was introduced by the distinguished ranking minority member of the subcommittee, Mr. MADIGAN. It was reported by the Committee on Energy and Commerce by voice vote.

Briefly, H.R. 1871 extends for 3 fiscal years the authorization of appropriations for the programs which comprise the Development Disabilities Assistance and Bill of Rights Act. These programs include: First, formula grants to States; second, grants to support protection and advocacy systems; third, grants for special projects; and fourth, grants to university affiliated facilities.

The committee amendment to the legislation eases the administrative requirements on States and requires each State to prepare a report on the extent to which they are currently meeting the needs of persons with developmental disabilities.

Mr. Speaker, the Federal developmental disabilities programs are vitally important to the millions of Americans with developmental disabilities. Their importance and success have made it enormously popular with the public, the Congress and the administration.

I urge support for the legislation. Mr. Speaker, I reserve the balance of my time.

Mr. LENT. Mr. Speaker, I yield myself such time as I may consume.

Mr. Speaker, I join the gentleman from Illinois, [Mr. BRUCE], a member of the Subcommittee on Health and the Environment in urging my colleagues to support H.R. 1871, the developmen-

tal disabilities assistance amendments of 1987. My colleague, Mr. MADIGAN, the ranking minority member of the subcommittee introduced this legislation on March 31, 1987, on behalf of the administration. H.R. 1871 reauthorizes the grant programs of the Developmental Disabilities Assistance and Bill of Rights Act for 3 fiscal years with such sums as may be necessary. The bill being considered under suspension of the rules today includes the provisions of H.R. 1871 as introduced and several amendments which enhance State flexibility in providing priority services to disabled individuals. It is my understanding that the administration does not oppose this legislation. Therefore, I urge my colleagues to join me in supporting H.R. 1871.

Mr. BRUCE. Mr. Speaker, I yield 5 minutes to the gentleman from Pennsylvania [Mr. WALGREN].

(Mr. WALGREN asked and was given permission to revise and extend his remarks.)

Mr. WALGREN. Mr. Speaker, I am pleased today to support the extension of the Developmental Disabilities Program. More than almost any other factor, this program has been the key to the rapid increase in sensitivity to the needs of the disabled and the protection of their rights.

I would like to underscore provisions in the bill I offered in subcommittee. The Developmental Disabilities Program has its origins in a 1963 law which applied only to individuals who were mentally retarded. Over time, Congress has expanded the definition so that those efforts now include a broad spectrum of functional limitations.

Currently under the law a "developmental disability" includes any severe chronic disability which—

- (A) is attributable to a mental or physical impairment or combination of mental and physical impairments;
- (B) is manifested before the person attains age 22;
- (C) is likely to continue indefinitely;
- (D) results in substantial functional limitations in 3 or more areas of life activity: (i) self-care; (ii) receptive and expressive language; (iii) learning; (iv) mobility; (v) self-direction; (vi) capacity for independent living; and (vii) economic self-sufficiency; and
- (E) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment or other services which are of lifelong or extended duration and are individually planned and coordinated.

In our hearings, we learned that many States construe the definition far more narrowly. As a result, many eligible individuals are not being reached. In many States, disabilities attributable to physical impairments such as cerebral palsy and epilepsy or developmental disabilities attributable to a combination of mental and physical impairments are not reached by the advocacy and planning of the State councils which administer this program.

The bill before us would require each State to develop a process to identify those individuals and report to Congress on ways of fully serving the developmentally disabled population. States would be required to hold public hearings to bring out the views and recommendations of developmentally disabled individuals and advocacy organizations.

The goal of the program is to assure that persons with developmental disabilities receive the care, treatment, and other services necessary to enable them to achieve their maximum potential through increased independence, productivity, and integration into the community." The failure of States to properly respond to the definition of developmental disabilities now results in this program being an unfulfilled promise to 1 million individuals and their families.

It is certainly my hope that this provision will send a strong signal to the States that they should move toward fully serving all of the developmentally disabled.

I would like to share with my colleagues the testimony of Ms. Eileen Cubarney, of Allison Park, PA, in which she poignantly and convincingly discusses the need for strong State programs.

TESTIMONY PRESENTED BY ELLEEN CUBARNEY

(On behalf of the National Society for Children and Adults With Autism, National Organization for Rare Disorders, Inc., Disability Rights Education and Defense Fund, United Cerebral Palsy Associations, Inc., National Spinal Cord Injury Association, National Network for Parent Centers, Spina Bifida Association of America, Epilepsy Foundation of America, Tourette Syndrome Association)

My name is Eileen Cubarney. I am the mother of six children. I have been engaged in advocacy on behalf of children and adults with disabilities for over twenty-five years. I am speaking today on behalf of United Cerebral Palsy Associations, Inc., Epilepsy Foundation of America, and seven other national organizations on behalf of individuals with the most severe disabilities. We share a common vision of an American society that provides opportunities for school age children with severe disabilities to be educated in public schools in a way that promotes interaction with their nonhandicapped peers; for adults with severe impairments to be employed in diverse settings earning a competitive wage; and for all children and adults with severe disabilities to live at home and in their home communities enjoying the benefits of friendship and continuing personal relationships.

My remarks today will be to paint for you a portrait of an American family: My family. The portrait is typical of thousands of families across the country who have sons and daughters with substantial functional limitations as defined in the Developmental Disabilities Act.

My testimony will describe the barriers we face as families seeking adequate and appropriate supports to enable our sons and daughters to learn, live, and work in their home communities.

My son David is twenty-one years old. He has a diagnosis of cerebral palsy and is further labelled as having quadriplegia. He can

talk but he cannot walk, feed himself, dress himself or attend to his bodily functions.

He has average to above average intelligence. Had we listened to the professionals when he was a baby and placed David in an institution our family would have been financially solvent today. Instead we chose to raise David at home and learn first hand about the struggles to earn his right to citizenship.

Our family has had only four vacations in eighteen years. Although Pennsylvania has a very large program of family support and respite services, David did not have the right label to access the system. We chose not to try and find a clinician who would re-label David as "mentally retarded" to access these services. To do so was too much of a compromise of his dignity and our integrity.

We paid for his therapies in his infant years and he attended the UCP nursery school which was funded by donations from the Elks Club. At age five he attended a private school for which the public school paid a per diem and we paid the rest of the tuition which exceeded the mortgage payment on our home.

At age thirteen with David's and our rights articulated in P.L. 94-142, the Education for all Handicapped Children's Act of 1975, and with the ongoing assistance and support of Congressman Walgren and his staff in Pittsburgh and an attorney whom we paid, we filed and won both a due process and a civil rights suit against the school district in order to have David removed from "special school" where he learned almost nothing and sent to a regular school with children of his own age who were not handicapped. David was the first student with quadriplegia to be "mainstreamed" in our community.

We won, but the school was so unprepared to meet his needs that they wanted to offer him a janitorial training program. With the help of local UCP staff and appropriate education plan was developed. For the past two years, as the result of another fight, David receives his education two days a week at the Independent Living Center where he is learning how to direct his own life and how to manage his attendant. He began receiving attendant services in 1985 as a result of Pennsylvania's pilot program in this area.

The attendant services have changed our family's role from that of David's constant caregivers to mother, father, brother and sister. This service has allowed me the opportunity to go to work for the first time in over twenty years and assist my husband's modest income in supporting our four children in college.

I am employed in the rehabilitation technology center at the Rehabilitation Institute of Pittsburgh. I see everyday what can be and is being achieved through technology for people like David and countless others with severe functional limitations with and without mental impairments. Yet how many individuals go without, go begging or are denied access to these and other necessary support services because their state has not yet chosen to put in place a service delivery system for all persons with developmental disabilities?

The individuals who fall under the umbrella term "developmentally disabled" are not a homogeneous group in terms of service needs.

I am here today representing over one million individuals who meet the definition of developmental disabilities but whose primary impairment is not a mental one. I call to your attention that the intent of the law is not being met consistently in all 50 states. . . . "to assist states to (A) assure that persons with developmental disabilities receive the care, treatment, and other services nec-

essary to enable them to achieve their maximum potential through independence, productivity, and integration into the community. . . ." The original intent of Congress in 1963 was to develop services to meet the needs of people with mental retardation. In 1970 and 1975, this intent was extended to people with other disabilities with similar service needs. And in 1978, the language was modified to assure that just persons with the most substantial disabilities received services.

The federal definition was purely categorical in 1970 (P.L. 91-517) and later evolved to a mixed categorical and functional one in 1975 (P.L. 94-103) which still had a reference to mental retardation. "Results in similar impairment of general intellectual functioning or adaptive behavior to that of mentally retarded persons or requires treatment and services similar to those required for such persons." In 1976, the Secretary of H.E.W. awarded a contract and appointed a task force to study the confusion and different interpretations in operationalizing the mixed definition. The task force recommended a functional approach to the definition—a non categorical definition which emphasized the complexity, pervasiveness, and substantiality of the disability condition(s). The proposed definition was included in the 1978 Act (P.L. 95-602) and continues today. The major differences, in this definition from the 1975 Act are:

No specific diagnostic categories or labels are used other than "mental and physical impairment."

The age limit for onset of the disability was raised from 18 to 22; and

The necessity of a substantial functional limitation in three or more areas of major life activity.

IMPACT OF CURRENT DEFINITION

The current definition excludes persons with mild disabilities, and, by eliminating categories makes it possible for persons with a wide range of diagnostic labels such as spina bifida, spinal cord injury, muscular dystrophy, multiple sclerosis, cystic fibrosis, Tourette Syndrome, and others to be included in the definition along with many persons from the more traditional diagnostic categories of mental retardation, cerebral palsy, epilepsy, and autism, including many persons with multiple mental and physical impairments. In fact, most prevalence estimates suggest that 1 to 1 1/2 million of the three million people classified as "developmentally disabled" are persons without mental impairments.

Though the disabilities are different, the common elements are that the origin of their disability was in the developmental period, that the individuals will need ongoing—possibly lifelong—support services and that goal of these services should be to increase independence, productivity, and community integration as stated in the 1984 Act (P.L. 98-527).

The definition adopted nearly ten years ago has had an impact on states but not nearly what some of us expected. Over 20 states still have a state agency which has an exclusive responsibility to persons with mental retardation.

In 1985, New Jersey was the first and only state to adopt the federal functional definition in state statute. The remaining states have adopted a variety of mixed categorical and functional definitions, many with a strong mental impairment overlay. In my home state of Pennsylvania our Developmental Disabilities Council has just this year committed some resources over the next three years to develop a plan for a coordinated comprehensive service system for all persons with developmental disabilities.

This decision has come about after five years of having a stated goal in the plan with no resources! Currently our single state agency is the Office of Mental Retardation in the Department of Public Welfare.

For more than eighty years, professionals have used an approach that focuses on individual deficits as the means of deciding whether a person was eligible for available services. The functional nature of the developmental disabilities definition should force a change in determining eligibility to a focus on the interaction between a person and his/her environment rather than focusing on deficits seen to be in the person.

#### CHANGING SERVICE PATTERNS

Changes in the boundaries of eligibility for services which result from adoption and implementation of the current definition will, in all likelihood, mean that the "newly eligible" people will require even more varied levels and types of supports. This means that past patterns of service delivery will not be able to adequately accommodate these differing demands. New service patterns will have to be developed, some old patterns abandoned, and agencies will of necessity learn to become more flexible in their dealing with individuals receiving services.

For example, in the area of community living, the preferred model of support service for someone with substantial functional limitations without a mental impairment is the person's own home or home with a roommate and a personal attendant hired and managed by the individual rather than placement in an "eight-bed" group home or other facility.

In the emerging area of supported employment, ongoing support for persons with developmental disabilities who are not mentally impaired will include a variety of services including transportation, physical, speech, and occupational therapies, medications, and applied technology rather than a job coach.

From these two illustrative examples, I trust you can see that the actual delivery of support services for the divergent population I represent today encompasses the same concepts but far different implementation strategies than for persons with developmental disabilities and mental impairment. This is what we urge you to require the Developmental Disabilities Councils to do more of—to assure the services required to support all persons with developmental disabilities, regardless of categorical diagnosis, be planned, demonstrated, and assured throughout the land.

Conclusion  
We have come a long way, but we believe it is now time to reconcile federal intent with state policy. As Dr. Elizabeth Boggs, a national expert on developmental disabilities, stated upon New Jersey's adoption of the federal definition into state statute in 1985, "We have had a non-accessing population of people—specifically, young adults with severe physical disabilities—who have had nowhere to go for assistance in putting it all together. These people really deserve to have an agency that can work for them."

I urge you to: (1) reaffirm that State Councils be involved in the system reform necessary within their respective states so that each state adopt the federal definition in a timely manner and (2) assure that each of the states meet the intent of the law by assigning the most appropriate agencies to be responsible and accountable to provide access to the full range of support services for individuals with developmental disabilities without mental impairments. Until

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that time, the promise of the Act will remain unfulfilled. Over one million citizens will continue to be more dependent than necessary on our resources and robbed of their human dignity and opportunity to contribute to community life.

Mr. WAXMAN. Mr. Speaker, the committee amendment to the legislation eases the administrative requirements on States which receive formula grant funds. Under current law, the authority of many States to support programs for the developmentally disabled are limited to statutorily specified Federal priority areas. A limited number of States are eligible to use block grant funds designated for Federal priorities for so-called optional services. The committee amendment would allow all States the authority to allocate funds to these optional services. In addition, the amendment lifts the current restriction on the number of Federal priority services that could receive formula grant funds.

In addition, the amendment requires States to prepare a report on the extent to which they are currently meeting the needs of persons with developmental disabilities. Mr. Speaker, on this point I want to note and commend the contribution of Mr. WALGREN, an active member of our subcommittee, to this legislation. The committee amendment contains provisions to address in part concerns presented to the subcommittee by his constituent, Mrs. Eileen Cubarney, on behalf of the Cerebral Palsy Foundation. Mrs. Cubarney testified earlier this year to the inadequate level of services available under State law to her physically disabled son. Although her son is developmentally disabled under the Federal definition of the Developmental Disabilities Assistance and Bill of Rights Act, because his disability is physical rather than emotional, he is not eligible for many support services under Pennsylvania law.

The committee was conerened by reports that States have been slow to provide adequate community and support services to individuals who are intellectually capable but physically disabled. The committee amendment requires States to begin a planning process which may lead to expanding eligibility to all persons in the State with developmental disabilities—regardless of whether the disability is of mental or physical origin. This is a serious problem and I appreciate the gentleman from Pennsylvania brining it to our attention.

Mr. Speaker, I urge support for the legislation.

Mr. LENT. Mr. Speaker, I have no further requests for time, and I yield back the balance of my time.

Mr. BRUCE. Mr. Speaker, I have no further requests for time, and I yield back the balance of my time.

The SPEAKER pro tempore. The question is on the motion offered by the gentleman from Illinois [Mr. BRUCE] that the House suspend the rules and pass the bill, H.R. 1817, as amended.

The question was taken; and (two-thirds having voted in favor thereof) the rules were suspended and the bill, as amended, was passed.

A motion to reconsider was laid on the table.

Mr. BRUCE. Mr. Speaker, I ask unanimous consent that the Committee on Energy and Commerce and the Committee on Education and Labor be

discharged from further consideration of the Senate bill (S. 1417) to revise and extend the Developmental Disabilities Assistance and Bill of Rights Act, and ask for its immediate consideration in the House.

The Clerk read the title of the Senate bill.

The SPEAKER pro tempore. Is there objection to the request of the gentleman from Illinois?

There was no objection.

The Clerk read the Senate bill, as follows: