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 reads 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."

SEC. 2. AUTHORIZATIONS OF APPROPRIATIONS.

The Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 600 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 142, by striking "$13,750,000" and all that follows in the first sentence and inserting "such sums as may be necessary for fiscal years 1986 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:

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

(i) to strengthen the role of the family as the primary care giver;"
Mr. BAUKER. 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 makes 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 development disabilities programs are vital, in importance, to 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. Bauck, a member of the Subcommittee on Health and the Environment in urging my colleagues to support H.R. 1871, the developmental 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. Wolinsky].

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 limitation in 3 or more areas of life activity: (i) self-care; (ii) receptive and expressive language; (iii) learning; (iv) mobility; (v) self-direction; and (vi) 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 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 Mrs. Eileen Carney of Allison Park, PA, in which she poignantly and convincingly discusses the need for strong State programs.

**Testimony Presented by Eileen Carney**

On behalf of the National Society for Children and Adults With Autism, National Comanagement and Osteogenesis Imperfecta Association, National Health Foundation for Children, National Association for the Education of the Disabled, Spina Bifida Association of America, Epileptic Foundation of America, Tourette Syndrome Association.

My name is Eileen Carney. I am the mother of six children. I have been engaged in the field of human and child development and with disabilities for over twenty-five years. I am speaking today on behalf of the United Cerebral Palsy Associations, Inc., Epilepsy Foundation of America, and seven other national organizations on behalf of individuals with brain injuries. We share a common vision of an American society that provides opportunities for school aged children with disabilities to be educated in public schools in a way that promotes interaction with their nonhandicapped peers. We believe the services to be employed in diverse settings earn a competitive wage and for all children and adults with severe disabilities to live at home and in their community.

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 with parents and children with residual disabilities.

My testimony will describe the barriers we face as families seeking adequate and appropriate services to enable our children and their families to live, work, and participate in their communities.

My story begins when I was twenty-one years old. I have a diagnosis of cerebral palsy and is further labelled as having quadraplegia. I can talk but I cannot walk, feed myself, dress myself or attend to my bodily functions.

He has average to above average intelligence. He was diagnosed when he was a baby and placed David in an institution. Our family would have been financially devastated.

Our family has had only two vacations in eighteen years. Although Pennsylvania has a very large program of family benefit and respite services, David did not have the right label to access the system. We chose not to try and find services and we were referred to 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 Congressional staff, we were able to have David removed from “special school” where he learned nothing and sent to a regular school with children of his own age who were not handicapped. David was the first student with quadraplegia to be “mainstreamed” in our community.

We won, but the school was so unprepared to meet his needs that they wanted to offer state aid but not yet change curriculum. With the help of local UCP staffing and appropriate education plan was developed. For the past two years we have had the opportunity to have David receive 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 1983 as a result of Pennsylvania’s plan for this area.

The attendant services have changed our family’s role from that of David’s constant caregivers to worker, brother and sister. This service has allowed me the opportunity to go to work for the first time in over twenty years. I care for 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 put in place a service delivery system for all persons with developmental disabilities?

The individuals and all 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 the intent of the law is not being met. In all 50 states . . . to assist states to (A) assure that persons with developmental disabilities receive the care, treatment, and other services necessary to enable them to achieve their maximum potential through independence, productivity, and integration into the community. . . . The 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. 94-143) which still had a refer- ence to mental retardation . . . results in significant 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 ineffective interpretations in operationalization of 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 conditions.

The proposed definition for the 1988 Act (P.L. 95-502) and continues today. The major differences in this definition from the 1975 act are:

No specificity of diagnostic categories or labels are used other than “mental and physical impairments.”

The age limit for onset of the disability was raised from 8 to 22.

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 no mental impairment. The categories makes it possible for persons with a wide range of diagnostic labels such as spina bifida, muscular dystrophy, multiple sclerosis, cystic fibrosis, Tourette Syndrome, and others to be excluded. In the current definition, persons would be excluded from the more traditional diagnostic categories of mental retardation, cerebral palsy, epilepsy, and autism. In the present day, millions of persons with multiple mental and physical impairments.

In fact, most prevalence estimates suggest that 1 in 5 adults and 3 of the 3 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.

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 1983, 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, the 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, the Office of Mental Health and 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
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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 will be modified and agencies will have to learn to become more flexible in their dealings 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 institutional setting.

In the emerging area of supported employment, ongoing support for persons with developmental disabilities, mentally impaired will include a variety of services including transportation, physical, speech and hearing therapies, medications, and applied technology rather than a job coach.

From these two illustrative examples, it is clear that the actual delivery of support services for the divergent populations who require supports today encompass the same concepts but for different implementation strategies than for persons with developmental disabilities who require mental impairment. This is what we urge you to require the Developmental Disabilities Councils to do more 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 Rogers, 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 need services 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 they can continue to adapt the federal definition, in a timely manner and (2) assure that each of the states meet the intent of the law by assuring that most appropriate services to be responsible and accountable to provide access to the full range of support services for individuals with developmental disabilities without mental impairments. Until 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 that the states impose on the 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 our 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's condition is not one for which eligibility to receive services under Pennsylvania law, the committee amendment requires States to begin a planning process which may lead to changes in eligibility to all persons in the State with developmental disabilities—regardless of whether the disability is of mental or physical origin.

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 therefor) 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.