106TH CONGRESS 1ST SESSION S. 1809

To improve service systems for individuals with developmental disabilities, and for other purposes.

IN THE SENATE OF THE UNITED STATES

October 27, 1999

Mr. JEFFORDS (for himself, Mr. KENNEDY, Mr. HARKIN, Mr. FRIST, Ms. COLLINS, Mr. WELLSTONE, Mr. REED, Mr. DODD, and Mrs. MURRAY) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

A BILL

To improve service systems for individuals with developmental disabilities, and for other purposes.

- 1 Be it enacted by the Senate and House of Representa-
- 2 tives of the United States of America in Congress assembled,

3 SECTION 1. SHORT TITLE; TABLE OF CONTENTS.

- 4 (a) SHORT TITLE.—This Act may be cited as the
- 5 "Developmental Disabilities Assistance and Bill of Rights
- 6 Act of 1999".
- 7 (b) TABLE OF CONTENTS.—The table of contents of
- 8 this Act is as follows:
 - Sec. 1. Short title; table of contents.

TITLE I—PROGRAMS FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

Subtitle A—General Provisions

- Sec. 101. Findings, purposes, and policy.
- Sec. 102. Definitions.
- Sec. 103. Records and audits.
- Sec. 104. Responsibilities of the Secretary.
- Sec. 105. Reports of the Secretary.
- Sec. 106. State control of operations.
- Sec. 107. Employment of individuals with disabilities.
- Sec. 108. Construction.
- Sec. 109. Rights of individuals with developmental disabilities.

Subtitle B—Federal Assistance to State Councils on Developmental Disabilities

- Sec. 121. Purpose.
- Sec. 122. State allotments.
- Sec. 123. Payments to the States for planning, administration, and services.
- Sec. 124. State plan.
- Sec. 125. State Councils on Developmental Disabilities and designated State agencies.
- Sec. 126. Federal and non-Federal share.
- Sec. 127. Withholding of payments for planning, administration, and services.
- Sec. 128. Appeals by States.
- Sec. 129. Authorization of appropriations.

Subtitle C-Protection and Advocacy of Individual Rights

- Sec. 141. Purpose.
- Sec. 142. Allotments and payments.
- Sec. 143. System required.
- Sec. 144. Administration.
- Sec. 145. Authorization of appropriations.

Subtitle D—National Network of University Centers for Excellence in Developmental Disabilities Education, Research, and Service

- Sec. 151. Grant authority.
- Sec. 152. Grant awards.
- Sec. 153. Purpose and scope of activities.
- Sec. 154. Applications.
- Sec. 155. Definition.
- Sec. 156. Authorization of appropriations.

Subtitle E—Projects of National Significance

- Sec. 161. Purpose.
- Sec. 162. Grant authority.
- Sec. 163. Authorization of appropriations.

TITLE II—FAMILY SUPPORT

- Sec. 201. Short title.
- Sec. 202. Findings, purposes, and policy.
- Sec. 203. Definitions and special rule.

- Sec. 204. Grants to States.
- Sec. 205. Application.
- Sec. 206. Designation of the lead entity.
- Sec. 207. Authorized activities.
- Sec. 208. Reporting.
- Sec. 209. Technical assistance.
- Sec. 210. Evaluation.
- Sec. 211. Projects of national significance.
- Sec. 212. Authorization of appropriations.

TITLE III—PROGRAM FOR DIRECT SUPPORT WORKERS WHO ASSIST INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

- Sec. 301. Findings.
- Sec. 302. Definitions.
- Sec. 303. Reaching up scholarship program.
- Sec. 304. Staff development curriculum authorization.
- Sec. 305. Authorization of appropriations.

TITLE IV—REPEAL

Sec. 401. Repeal.

TITLE I—PROGRAMS FOR INDI VIDUALS WITH DEVELOP MENTAL DISABILITIES

4 Subtitle A—General Provisions

5 SEC. 101. FINDINGS, PURPOSES, AND POLICY.

6 (a) FINDINGS.—Congress finds that—

7 (1) disability is a natural part of the human ex-8 perience that does not diminish the right of individ-9 uals with developmental disabilities to live independ-10 ently, to exert control and choice over their own 11 lives, and to fully participate in and contribute to 12 their communities through full integration and inclu-13 sion in the economic, political, social, cultural, and 14 educational mainstream of United States society;

(2) in 1999, there are between 3,200,000 and
4,500,000 individuals with developmental disabilities
in the United States, and recent studies indicate
that individuals with developmental disabilities com-
prise between 1.2 and 1.65 percent of the United
States population;
(3) individuals whose disabilities occur during
their developmental period frequently have severe
disabilities that are likely to continue indefinitely;
(4) individuals with developmental disabilities
often encounter discrimination in the provision of
critical services, such as services in the areas of em-
phasis (as defined in section 102);
(5) individuals with developmental disabilities
are at greater risk than the general population of
abuse, neglect, financial and sexual exploitation, and
the violation of their legal and human rights;
(6) a substantial portion of individuals with de-
velopmental disabilities and their families do not
have access to appropriate support and services, in-
cluding access to assistive technology, from generic
and specialized service systems, and remain unserved
or underserved;
(7) individuals with developmental disabilities
often require lifelong community services, individual-

ized supports, and other forms of assistance, that
 are most effective when provided in a coordinated
 manner;

4 (8) there is a need to ensure that services, sup5 ports, and other assistance are provided in a cul6 turally competent manner, that ensures that individ7 uals from racial and ethnic minority backgrounds
8 are fully included in all activities provided under this
9 title;

10 (9) family members, friends, and members of 11 the community can play an important role in en-12 hancing the lives of individuals with developmental 13 disabilities, especially when the family members, 14 friends, and community members are provided with 15 the necessary community services, individualized 16 supports, and other forms of assistance;

(10) current research indicates that 88 percent
of individuals with developmental disabilities live
with their families or in their own households;

(11) many service delivery systems and communities are not prepared to meet the impending needs
of the 479,862 adults with developmental disabilities
who are living at home with parents who are 60
years old or older and who serve as the primary
caregivers of the adults;

(12) in almost every State, individuals with de velopmental disabilities are waiting for appropriate
 services in their communities, in the areas of empha sis;

5 (13) the public needs to be made more aware
6 of the capabilities and competencies of individuals
7 with developmental disabilities, particularly in cases
8 in which the individuals are provided with necessary
9 services, supports, and other assistance;

(14) as increasing numbers of individuals with
developmental disabilities are living, learning, working, and participating in all aspects of community
life, there is an increasing need for a well trained
workforce that is able to provide the services, supports, and other forms of direct assistance required
to enable the individuals to carry out those activities;

17 (15) there needs to be greater effort to recruit
18 individuals from minority backgrounds into profes19 sions serving individuals with developmental disabil20 ities and their families;

(16) the goals of the Nation properly include a
goal of providing individuals with developmental disabilities with the information, skills, opportunities,
and support to—

1	(A) make informed choices and decisions
2	about their lives;
3	(B) live in homes and communities in
4	which such individuals can exercise their full
5	rights and responsibilities as citizens;
6	(C) pursue meaningful and productive
7	lives;
8	(D) contribute to their families, commu-
9	nities, and States, and the Nation;
10	(E) have interdependent friendships and
11	relationships with other persons;
12	(F) live free of abuse, neglect, financial
13	and sexual exploitation, and violations of their
14	legal and human rights; and
15	(G) achieve full integration and inclusion
16	in society, in an individualized manner, con-
17	sistent with the unique strengths, resources,
18	priorities, concerns, abilities, and capabilities of
19	each individual; and
20	(17) as the Nation, States, and communities
21	maintain and expand community living options for
22	individuals with developmental disabilities, there is a
23	need to evaluate the access to those options by indi-
24	viduals with developmental disabilities and the ef-

7

fects of those options on individuals with develop mental disabilities.

3 (b) PURPOSE.—The purpose of this title is to assure 4 that individuals with developmental disabilities and their 5 families participate in the design of and have access to needed community services, individualized supports, and 6 7 other forms of assistance that promote self-determination, 8 independence, productivity, and integration and inclusion 9 in all facets of community life, through culturally com-10 petent programs authorized under this title, including 11 specifically-

12 (1) State Councils on Developmental Disabil13 ities in each State to engage in advocacy, capacity
14 building, and systemic change activities that—

15 (A) are consistent with the purpose de16 scribed in this subsection and the policy de17 scribed in subsection (c); and

(B) contribute to a coordinated, consumerand family-centered, consumer- and family-directed, comprehensive system that includes
needed community services, individualized supports, and other forms of assistance that promote self-determination for individuals with developmental disabilities and their families;

1	(2) protection and advocacy systems in each
2	State to protect the legal and human rights of indi-
3	viduals with developmental disabilities;
4	(3) University Centers for Excellence in Devel-
5	opmental Disabilities Education, Research, and
6	Service—
7	(A) to provide interdisciplinary pre-service
8	preparation and continuing education of stu-
9	dents and fellows, which may include the prepa-
10	ration and continuing education of leadership,
11	direct service, clinical, or other personnel to
12	strengthen and increase the capacity of States
13	and communities to achieve the purpose of this
14	title;
15	(B) to provide community services—
16	(i) that provide training and technical
17	assistance for individuals with develop-
18	mental disabilities, their families, profes-
19	sionals, paraprofessionals, policymakers,
20	students, and other members of the com-
21	munity; and
22	(ii) that may provide services, sup-
23	ports, and assistance for the persons de-
24	scribed in clause (i) through demonstration
25	and model activities;

1 (C) to conduct research, which may include 2 basic or applied research, evaluation, and the 3 analysis of public policy in areas that affect or 4 could affect, either positively or negatively, indi-5 viduals with developmental disabilities and their 6 families; and 7 (D) to disseminate information related to 8 activities undertaken to address the purpose of 9 this title, especially dissemination of informa-10 tion that demonstrates that the network author-11 ized under this subtitle is a national and inter-12 national resource that includes specific sub-

13 stantive areas of expertise that may be accessed
14 and applied in diverse settings and cir15 cumstances; and

16 (4) funding for—

17 (A) national initiatives to collect necessary
18 data on issues that are directly or indirectly rel19 evant to the lives of individuals with develop20 mental disabilities;

(B) technical assistance to entities who engage in or intend to engage in activities consistent with the purpose described in this subsection or the policy described in subsection (c);
and

(C) other nationally significant activities.
 (c) POLICY.—It is the policy of the United States
 that all programs, projects, and activities receiving assist ance under this title shall be carried out in a manner con sistent with the principles that—

6 (1) individuals with developmental disabilities, 7 including those with the most severe developmental 8 disabilities, are capable of self-determination, inde-9 pendence, productivity, and integration and inclusion 10 in all facets of community life, but often require the 11 provision of community services, individualized sup-12 ports, and other forms of assistance;

13 (2) individuals with developmental disabilities 14 and their families have competencies, capabilities, 15 and personal goals that should be recognized, sup-16 ported, and encouraged, and any assistance to such 17 individuals should be provided in an individualized 18 manner, consistent with the unique strengths, re-19 sources, priorities, concerns, abilities, and capabili-20 ties of such individuals;

(3) individuals with developmental disabilities
and their families are the primary decisionmakers
regarding the services and supports such individuals
and their families receive, including regarding choosing where the individuals live from available options,

and play decisionmaking roles in policies and pro grams that affect the lives of such individuals and
 their families;

4 (4) services, supports, and other assistance
5 should be provided in a manner that demonstrates
6 respect for individual dignity, personal preferences,
7 and cultural differences;

8 (5) specific efforts must be made to ensure that 9 individuals from racial and ethnic minority back-10 grounds and their families enjoy increased and 11 meaningful opportunities to access and use commu-12 nity services, individualized supports, and other 13 forms of assistance available to other individuals 14 with developmental disabilities and their families;

15 (6) recruitment efforts in disciplines related to 16 developmental disabilities relating to pre-service 17 training, community training, practice, administra-18 tion, and policymaking must focus on bringing larg-19 er numbers of racial and ethnic minorities into the 20 disciplines in order to provide appropriate skills, 21 knowledge, role models, and sufficient personnel to 22 address the growing needs of an increasingly diverse 23 population;

24 (7) with education and support, communities25 can be accessible to and responsive to the needs of

individuals with developmental disabilities and their
 families and are enriched by full and active partici pation in community activities, and contributions, by
 individuals with developmental disabilities and their
 families;

6 (8) individuals with developmental disabilities 7 have access to opportunities and the necessary sup-8 port to be included in community life, have inter-9 dependent relationships, live in homes and commu-10 nities, and make contributions to their families, com-11 munities, and States, and the Nation;

12 (9) efforts undertaken to maintain or expand 13 community-based living options for individuals with 14 disabilities should be monitored in order to deter-15 mine and report to appropriate individuals and enti-16 ties the extent of access by individuals with develop-17 mental disabilities to those options and the extent of 18 compliance by entities providing those options with 19 quality assurance standards;

(10) families of children with developmental disabilities need to have access to and use of safe and
appropriate child care and before-school and afterschool programs, in the most integrated settings, in
order to enrich the participation of the children in
community life;

(11) individuals with developmental disabilities
 need to have access to and use of public transpor tation, in order to be independent and directly con tribute to and participate in all facets of community
 life; and

6 (12) individuals with developmental disabilities 7 need to have access to and use of recreational, lei-8 sure, and social opportunities in the most integrated 9 settings, in order to enrich their participation in 10 community life.

11 SEC. 102. DEFINITIONS.

12 In this title:

13 (1) AMERICAN INDIAN CONSORTIUM.—The term 14 "American Indian Consortium" means any confed-15 eration of 2 or more recognized American Indian 16 tribes, created through the official action of each 17 participating tribe, that has a combined total resi-18 dent population of 150,000 enrolled tribal members 19 and a contiguous territory of Indian lands in 2 or 20 more States.

(2) AREAS OF EMPHASIS.—The term "areas of
emphasis" means the areas related to quality assurance activities, education activities and early intervention activities, child care-related activities, healthrelated activities, employment-related activities,

housing-related activities, transportation-related ac tivities, recreation-related activities, and other serv ices available or offered to individuals in a commu nity, including formal and informal community sup ports, that affect their quality of life.

6 (3)Assistive TECHNOLOGY DEVICE.—The term "assistive technology device" means any item, 7 8 piece of equipment, or product system, whether ac-9 quired commercially, modified or customized, that is 10 used to increase, maintain, or improve functional ca-11 pabilities of individuals with developmental disabil-12 ities.

(4) ASSISTIVE TECHNOLOGY SERVICE.—The
term "assistive technology service" means any service that directly assists an individual with a developmental disability in the selection, acquisition, or use
of an assistive technology device. Such term
includes—

19 (A) conducting an evaluation of the needs
20 of an individual with a developmental disability,
21 including a functional evaluation of the indi22 vidual in the individual's customary environ23 ment;

24 (B) purchasing, leasing, or otherwise pro-25 viding for the acquisition of an assistive tech-

1	nology device by an individual with a develop-
2	mental disability;
3	(C) selecting, designing, fitting, custom-
4	izing, adapting, applying, maintaining, repair-
5	ing or replacing an assistive technology device;
6	(D) coordinating and using another ther-
7	apy, intervention, or service with an assistive
8	technology device, such as a therapy, interven-
9	tion, or service associated with an education or
10	rehabilitation plan or program;
11	(E) providing training or technical assist-
12	ance for an individual with a developmental dis-
13	ability, or, where appropriate, a family member,
14	guardian, advocate, or authorized representative
15	of an individual with a developmental disability;
16	and
17	(F) providing training or technical assist-
18	ance for professionals (including individuals
19	providing education and rehabilitation services),
20	employers, or other individuals who provide
21	services to, employ, or are otherwise substan-
22	tially involved in the major life functions of, an
23	individual with developmental disabilities.
24	(5) CENTER.—The term "Center" means a
25	University Center for Excellence in Developmental

Disabilities Education, Research, and Service estab lished under subtitle D.

(6) CHILD CARE-RELATED ACTIVITIES.—The
term "child care-related activities" means advocacy,
capacity building, and systemic change activities
that result in families of children with developmental
disabilities having access to and use of child care
services, including before-school, after-school, and
out-of-school services, in their communities.

10 (7) CULTURALLY COMPETENT.—The term "cul-11 turally competent", used with respect to services, 12 supports, or other assistance, means services, sup-13 ports, or other assistance that is conducted or pro-14 vided in a manner that is responsive to the beliefs, 15 interpersonal styles, attitudes, language, and behav-16 iors of individuals who are receiving the services, 17 supports, or other assistance, and in a manner that 18 has the greatest likelihood of ensuring their max-19 imum participation in the program involved.

20 (8) DEVELOPMENTAL DISABILITY.—

21 (A) IN GENERAL.—The term "develop22 mental disability" means a severe, chronic dis23 ability of an individual that—

1	(i) is attributable to a mental or phys-
2	ical impairment or combination of mental
3	and physical impairments;
4	(ii) is manifested before the individual
5	attains age 22;
6	(iii) is likely to continue indefinitely;
7	(iv) results in substantial functional
8	limitations in 3 or more of the following
9	areas of major life activity:
10	(I) Self-care.
11	(II) Receptive and expressive lan-
12	guage.
13	(III) Learning.
14	(IV) Mobility.
15	(V) Self-direction.
16	(VI) Capacity for independent
17	living.
18	(VII) Economic self-sufficiency;
19	and
20	(v) reflects the individual's need for a
21	combination and sequence of special, inter-
22	disciplinary, or generic services, individual-
23	ized supports, or other forms of assistance
24	that are of lifelong or extended duration

1	and are individually planned and coordi-
2	nated.
3	(B) INFANTS AND YOUNG CHILDREN.—An
4	individual from birth to age 9, inclusive, who
5	has a substantial developmental delay or spe-
6	cific congenital or acquired condition, may be
7	considered to have a developmental disability
8	without meeting 3 or more of the criteria de-
9	scribed in clauses (i) through (v) of subpara-
10	graph (A) if the individual, without services and
11	supports, has a high probability of meeting
12	those criteria later in life.
13	(9) Early intervention activities.—The
14	term "early intervention activities" means advocacy,
15	capacity building, and systemic change activities pro-
16	vided to individuals described in paragraph (8)(B)
17	and their families to enhance—
18	(A) the development of the individuals to
19	maximize their potential; and
20	(B) the capacity of families to meet the
21	special needs of the individuals.
22	(10) Education activities.—The term "edu-
23	cation activities" means advocacy, capacity building,
24	and systemic change activities that result in individ-
25	uals with developmental disabilities being able to ac-

cess appropriate supports and modifications when
 necessary, to maximize their educational potential,
 to benefit from lifelong educational activities, and to
 be integrated and included in all facets of student
 life.

6 (11) Employment-related activities.—The term "employment-related activities" means advo-7 8 cacy, capacity building, and systemic change activi-9 ties that result in individuals with developmental dis-10 abilities acquiring, retaining, or advancing in paid 11 employment, including supported employment or 12 self-employment, in integrated settings in a commu-13 nity.

14 (12) FAMILY SUPPORT SERVICES.—

15 (A) IN GENERAL.—The term "family support services" means services, supports, and
other assistance, provided to families with members who have developmental disabilities, that
are designed to—

20 (i) strengthen the family's role as pri21 mary caregiver;

(ii) prevent inappropriate out-of-thehome placement of the members and maintain family unity; and

(iii) reunite families with members
 who have been placed out of the home
 whenever possible.

4 (B) SPECIFIC SERVICES.—Such term in-5 cludes respite care, provision of rehabilitation 6 technology and assistive technology, personal 7 assistance services, parent training and coun-8 seling, support for families headed by aging 9 caregivers, vehicular and home modifications, 10 and assistance with extraordinary expenses, as-11 sociated with the needs of individuals with de-12 velopmental disabilities.

(13) HEALTH-RELATED ACTIVITIES.—The term
"health-related activities" means advocacy, capacity
building, and systemic change activities that result
in individuals with developmental disabilities having
access to and use of coordinated health, dental, mental health, and other human and social services, including prevention activities, in their communities.

(14) HOUSING-RELATED ACTIVITIES.—The
term "housing-related activities" means advocacy,
capacity building, and systemic change activities
that result in individuals with developmental disabilities having access to and use of housing and housing supports and services in their communities, in-

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1	cluding assistance related to renting, owning, or
2	modifying an apartment or home.
3	(15) Inclusion.—The term "inclusion", used
4	with respect to individuals with developmental dis-
5	abilities, means the acceptance and encouragement
6	of the presence and participation of individuals with
7	developmental disabilities, by individuals without dis-
8	abilities, in social, educational, work, and community
9	activities, that enables individuals with develop-
10	mental disabilities to—
11	(A) have friendships and relationships with
12	individuals and families of their own choice;
13	(B) live in homes close to community re-
14	sources, with regular contact with individuals
15	without disabilities in their communities;
16	(C) enjoy full access to and active partici-
17	pation in the same community activities and
18	types of employment as individuals without dis-
19	abilities; and
20	(D) take full advantage of their integration
21	into the same community resources as individ-
22	uals without disabilities, living, learning, work-
23	ing, and enjoying life in regular contact with in-
24	dividuals without disabilities.

1	(16) Individualized supports.—The term
2	"individualized supports" means supports that—
3	(A) enable an individual with a develop-
4	mental disability to exercise self-determination,
5	be independent, be productive, and be inte-
6	grated and included in all facets of community
7	life;
8	(B) are designed to—
9	(i) enable such individual to control
10	such individual's environment, permitting
11	the most independent life possible;
12	(ii) prevent placement into a more re-
13	strictive living arrangement than is nec-
14	essary; and
15	(iii) enable such individual to live,
16	learn, work, and enjoy life in the commu-
17	nity; and
18	(C) include—
19	(i) early intervention services;
20	(ii) respite care;
21	(iii) personal assistance services;
22	(iv) family support services;
23	(v) supported employment services;

1	(vi) support services for families head-
2	ed by aging caregivers of individuals with
3	developmental disabilities; and
4	(vii) provision of rehabilitation tech-
5	nology and assistive technology, and assist-
6	ive technology services.
7	(17) INTEGRATION.—The term "integration",
8	used with respect to individuals with developmental
9	disabilities, means exercising the equal right of indi-
10	viduals with developmental disabilities to access and
11	use the same community resources as are used by
12	and available to other citizens.
13	(18) Not-for-Profit.—The term "not-for-
14	profit", used with respect to an agency, institution,
15	or organization, means an agency, institution, or or-
16	ganization that is owned or operated by 1 or more
17	corporations or associations, no part of the net earn-
18	ings of which inures, or may lawfully inure, to the
19	benefit of any private shareholder or individual.
20	(19) PERSONAL ASSISTANCE SERVICES.—The
21	term "personal assistance services" means a range
22	of services, provided by 1 or more individuals, de-
23	signed to assist an individual with a disability to
24	perform daily activities, including activities on or off
25	a job that such individual would typically perform if

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1	such individual did not have a disability. Such serv-
2	ices shall be designed to increase such individual's
3	control in life and ability to perform everyday activi-
4	ties, including activities on or off a job.
5	(20) PREVENTION ACTIVITIES.—The term "pre-
6	vention activities" means activities that address the
7	causes of developmental disabilities and the exacer-
8	bation of functional limitation, such as activities
9	that—
10	(A) eliminate or reduce the factors that
11	cause or predispose individuals to developmental
12	disabilities or that increase the prevalence of
13	developmental disabilities;
14	(B) increase the early identification of
15	problems to eliminate circumstances that create
16	or increase functional limitations; and
17	(C) mitigate against the effects of develop-
18	mental disabilities throughout the lifespan of an
19	individual.
20	(21) PRODUCTIVITY.—The term "productivity"
21	means—
22	(A) engagement in income-producing work
23	that is measured by increased income, improved
24	employment status, or job advancement; or

(B) engagement in work that contributes
 to a household or community.
 (22) PROTECTION AND ADVOCACY SYSTEM.—
 The term "protection and advocacy system" means
 a protection and advocacy system established in ac cordance with section 143.