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Folder Title:

Disability--DD [Developmental Disabilities] Act

Stack:

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96

Section:

5

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Andrea Kane

Record Type: Record

To: Jonathan M. Young/WHO/EOP@EOP
cc: Christina S. Ho/OPD/EOP@EOP
bcc:
Subject: Re: HR 4920/S. 1809 

thanks - very helpful
Jonathan M. Young

 Jonathan M. Young
09/26/2000 09:24:07 AM

Record Type: Record

To: Andrea Kane/OPD/EOP@EOP
cc:
bcc:
Subject: Re: HR 4920/S. 1809 

The DD Act is of huge importance to the community and they are hoping for a signing ceremony (a small Oval photo-op type of signing). The Reauthorization has passed both houses, and now they're only trying to work out minor technical differences between the two versions. The Administration has supported the reauthorization, and folks at HHS and DOEd have worked hard on it. I'm not sure, however, of any major SAP or other official statement we've put out. I'll check on that and get back to you.
Andrea Kane

Andrea Kane

Record Type: Record

To: Jonathan M. Young/WHO/EOP@EOP
cc: Christina S. Ho/OPD/EOP@EOP
Subject: HR 4920/S. 1809

do you know anything about this Developmental Disabilities Assistance and Bill of Rights Act? If so, can you give us a bit of background? It seems to be moving and we're trying to figure out whether this is something the Administratio has taken a position on in the past, where the various groups are, etc.

thanks!

OFFICE OF MANAGEMENT AND BUDGET
Legislative Reference Division
Labor-Welfare-Personnel Branch

TO: Andrea Kane b 7431
Christine Ho

FROM: K. Blank
395 7363

Date: 09 / 26 / 00

Time: : AM/PM

Comments:

11/99 HHS letter on S1809 - developmental disab Act

Number of Pages (including cover sheet): 3

November 2, 1999

The Honorable James M. Jeffords
Chairman, Committee on Health, Education, Labor
and Pensions
U.S. Senate
Washington, D.C. 20510

Dear Mr. Chairman:

We take this opportunity to inform you of the views of the Department of Health and Human Services (HHS) on S. 1809, the "Developmental Disabilities Assistance and Bill of Rights Act of 1999".

The Administration appreciates the progress that has been made in the 106th Congress toward the reauthorization of the programs under the Developmental Disabilities Assistance and Bill of Rights Act, due in large part to the role that you, Senator Kennedy and Senator Harkin have played in supporting these vital programs for people with developmental disabilities and their families. We support your efforts and look forward to continuing to work with you and your colleagues in a bipartisan fashion to complete final action on this important legislation.

We would like to express our deep appreciation for incorporating into S. 1809 so many of the provisions put forth by the Administration in our proposal. Of particular note is the inclusion of performance-based accountability requirements for these programs to facilitate our compliance with the Government Performance and Results Act (GPRA).

The bill adopts other Administration proposals such as an extended reauthorization period; improved coordination and collaboration among the Councils on Developmental Disabilities, Protection and Advocacy and University Affiliated Programs; the reorganization and streamlining of the University Affiliated Programs (renamed University Centers for Excellence in Developmental Disabilities); and the authority to enter into interagency agreements with other Federal agencies to carry out Projects of National Significance activities.

We thank you again for your outstanding leadership throughout this process. We look forward to working with you on remaining issues to achieve our mutual goal of reauthorizing the Developmental Disabilities Assistance and Bill of Rights Act.

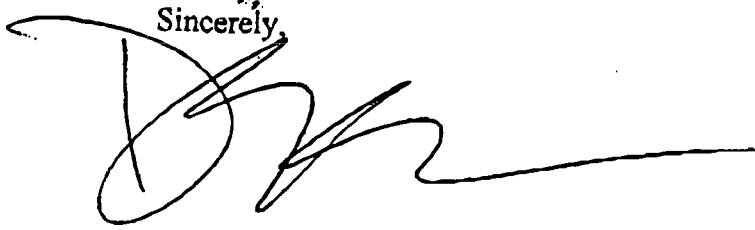
S09, 00

CKMMDH129

OMB Feedback
11/10

The Office of Management and Budget has advised that there is no objection to the transmittal of this report to Congress from the standpoint of the Administration's program.

Sincerely,



Donna E. Shalala
Secretary

809, 00

CKMMD4121

OMB Feedback
11/10

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.

**1 TITLE I—PROGRAMS FOR INDI-
 2 VIDUALS WITH DEVELOP-
 3 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;

1 (2) in 1999, there are between 3,200,000 and
2 4,500,000 individuals with developmental disabilities
3 in the United States, and recent studies indicate
4 that individuals with developmental disabilities com-
5 prise between 1.2 and 1.65 percent of the United
6 States population;

7 (3) individuals whose disabilities occur during
8 their developmental period frequently have severe
9 disabilities that are likely to continue indefinitely;

10 (4) individuals with developmental disabilities
11 often encounter discrimination in the provision of
12 critical services, such as services in the areas of em-
13 phasis (as defined in section 102);

14 (5) individuals with developmental disabilities
15 are at greater risk than the general population of
16 abuse, neglect, financial and sexual exploitation, and
17 the violation of their legal and human rights;

18 (6) a substantial portion of individuals with de-
19 velopmental disabilities and their families do not
20 have access to appropriate support and services, in-
21 cluding access to assistive technology, from generic
22 and specialized service systems, and remain unserved
23 or underserved;

24 (7) individuals with developmental disabilities
25 often require lifelong community services, individual-

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

4 (8) there is a need to ensure that services, sup-
5 ports, and other assistance are provided in a cul-
6 turally competent manner, that ensures that individ-
7 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;

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

20 (11) many service delivery systems and commu-
21 nities are not prepared to meet the impending needs
22 of the 479,862 adults with developmental disabilities
23 who are living at home with parents who are 60
24 years old or older and who serve as the primary
25 caregivers of the adults;

1 (12) in almost every State, individuals with de-
2 velopmental disabilities are waiting for appropriate
3 services in their communities, in the areas of empha-
4 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;

10 (14) as increasing numbers of individuals with
11 developmental disabilities are living, learning, work-
12 ing, and participating in all aspects of community
13 life, there is an increasing need for a well trained
14 workforce that is able to provide the services, sup-
15 ports, and other forms of direct assistance required
16 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 profes-
19 sions serving individuals with developmental disabil-
20 ities and their families;

21 (16) the goals of the Nation properly include a
22 goal of providing individuals with developmental dis-
23 abilities with the information, skills, opportunities,
24 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-

1 fects of those options on individuals with develop-
2 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
6 needed community services, individualized supports, and
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 Disabil-
13 ities in each State to engage in advocacy, capacity
14 building, and systemic change activities that—

15 (A) are consistent with the purpose de-
16 scribed in this subsection and the policy de-
17 scribed in subsection (c); and

18 (B) contribute to a coordinated, consumer-
19 and family-centered, consumer- and family-di-
20 rected, comprehensive system that includes
21 needed community services, individualized sup-
22 ports, and other forms of assistance that pro-
23 mote self-determination for individuals with de-
24 velopmental 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 cir-
15 cumstances; and

16 (4) funding for—

17 (A) national initiatives to collect necessary
18 data on issues that are directly or indirectly rel-
19 evant to the lives of individuals with develop-
20 mental disabilities;

21 (B) technical assistance to entities who en-
22 gage in or intend to engage in activities con-
23 sistent with the purpose described in this sub-
24 section or the policy described in subsection (c);
25 and

1 (C) other nationally significant activities.

2 (c) POLICY.—It is the policy of the United States
3 that all programs, projects, and activities receiving assist-
4 ance under this title shall be carried out in a manner con-
5 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;

21 (3) individuals with developmental disabilities
22 and their families are the primary decisionmakers
23 regarding the services and supports such individuals
24 and their families receive, including regarding choos-
25 ing where the individuals live from available options,

1 and play decisionmaking roles in policies and pro-
2 grams that affect the lives of such individuals and
3 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, communities
25 can be accessible to and responsive to the needs of

1 individuals with developmental disabilities and their
2 families and are enriched by full and active partici-
3 pation in community activities, and contributions, by
4 individuals with developmental disabilities and their
5 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;

20 (10) families of children with developmental dis-
21 abilities need to have access to and use of safe and
22 appropriate child care and before-school and after-
23 school programs, in the most integrated settings, in
24 order to enrich the participation of the children in
25 community life;

1 (11) individuals with developmental disabilities
 2 need to have access to and use of public transpor-
 3 tation, in order to be independent and directly con-
 4 tribute to and participate in all facets of community
 5 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.

21 (2) **AREAS OF EMPHASIS.**—The term “areas of
 22 emphasis” means the areas related to quality assur-
 23 ance activities, education activities and early inter-
 24 vention activities, child care-related activities, health-
 25 related activities, employment-related activities,

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

6 (3) ASSISTIVE TECHNOLOGY DEVICE.—The
7 term “assistive technology device” means any item,
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.

13 (4) ASSISTIVE TECHNOLOGY SERVICE.—The
14 term “assistive technology service” means any serv-
15 ice that directly assists an individual with a develop-
16 mental disability in the selection, acquisition, or use
17 of an assistive technology device. Such term
18 includes—

19 (A) conducting an evaluation of the needs
20 of an individual with a developmental disability,
21 including a functional evaluation of the indi-
22 vidual in the individual’s customary environ-
23 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

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

3 (6) CHILD CARE-RELATED ACTIVITIES.—The
 4 term “child care-related activities” means advocacy,
 5 capacity building, and systemic change activities
 6 that result in families of children with developmental
 7 disabilities having access to and use of child care
 8 services, including before-school, after-school, and
 9 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 “develop-
 22 mental disability” means a severe, chronic dis-
 23 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.

(11) EMPLOYMENT-RELATED ACTIVITIES.—The term “employment-related activities” means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities acquiring, retaining, or advancing in paid employment, including supported employment or self-employment, in integrated settings in a community.

(12) FAMILY SUPPORT SERVICES.—

(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—

(i) strengthen the family’s role as primary caregiver;

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

1 (iii) reunite families with members
 2 who have been placed out of the home
 3 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 (13) HEALTH-RELATED ACTIVITIES.—The term
 14 “health-related activities” means advocacy, capacity
 15 building, and systemic change activities that result
 16 in individuals with developmental disabilities having
 17 access to and use of coordinated health, dental, men-
 18 tal health, and other human and social services, in-
 19 cluding prevention activities, in their communities.

20 (14) HOUSING-RELATED ACTIVITIES.—The
 21 term “housing-related activities” means advocacy,
 22 capacity building, and systemic change activities
 23 that result in individuals with developmental disabil-
 24 ities having access to and use of housing and hous-
 25 ing supports and services in their communities, in-

1 including 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

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

1 (B) engagement in work that contributes
2 to a household or community.

3 (22) PROTECTION AND ADVOCACY SYSTEM.—

4 The term “protection and advocacy system” means
5 a protection and advocacy system established in ac-
6 cordance with section 143.



U.S. Department of Justice

Office of Legislative Affairs

Washington, D.C. 20530

September 22, 2000

MEMORANDUM

TO: Karen N. Blank, OMB

FROM: Velma Taylor, DOJ

RE: H.R. 4920, Developmental Disabilities Assistance and Bill of Rights Act of 2000 (LRM-KNB58)

The Department of Justice has reviewed H.R. 4920, and offer the following concerns. Due to time limitation in which we had to review this bill, these comments are being provided in memoranda form in order to expedite your receipt.

Constitutional Concerns

First, section 102(32) contains the definition of "Unserved and Underserved," which states "the term 'unserved and underserved' includes populations such as individuals ..." Under a subsequent provision that authorizes grants to "University Centers for Excellence in Developmental Disabilities Education, Research, and Service," *see* § 151(a), the Secretary of Health and Human Services would possess the discretion to make additional grants to Centers or to additional Centers

(d) for States or populations that are unserved or underserved by Centers due to such factors as

- (1) population;
- (2) a high concentration of rural or urban areas; or
- (3) a high concentration of unserved or underserved populations.

§ 152(d).

We believe that if "such as" in section 102(32) were interpreted simply to permit the Secretary to determine, when deciding how to award the grants, that certain racial and ethnic minority groups are unserved or underserved and therefore should receive services, then the provision does not raise constitutional concerns. Thus, in implementing section 152(d), the Secretary could ensure that a Center receiving funds because of a high concentration of racial and ethnic minorities was receiving those funds only because the Secretary determined that such

minorities were unserved or underserved. If, however, the provision is interpreted to mean that individuals from racial and ethnic minority backgrounds automatically qualify as unserved and underserved populations, we believe it likely that a court would require the government to demonstrate that the provision is narrowly tailored to serve a compelling government interest. *See Adarand Constructors Inc. v. Peña*, 515 U.S. 200, 237 (1995).

Title II of the bill contains a similar provision. Under section 204(a) the Secretary would award grants to states to serve families of children with developmental disabilities. *See* § 204(a). Section 204(e)(3) would establish the priorities for the distribution of these grants.

As with section 152(d), if section 204(e)(3) were interpreted simply to permit the Secretary to determine, when deciding how to award the grants, that certain racial and ethnic minority groups are unserved or underserved and therefore should receive services, then the provision does not raise constitutional concerns. If, however, the provision is interpreted to mean that individuals from racial and ethnic minority backgrounds automatically qualify as unserved and underserved populations, then we believe it likely that a court would hold that the provision triggers strict scrutiny.¹

Second, section 154(a)(3)(E)(iii) would require an entity seeking funding as a “University Center for Excellence in Developmental Disabilities Education, Research, and Service” to submit an application to the Secretary. That application must include an assurance that the Center would “establish a consumer advisory committee” that, *inter alia*, “reflects the racial and ethnic diversity of the State” in which the center would be located. This requirement might be viewed as a race-based classification. If a court did view the provision in such a manner, the government would have to demonstrate that the provision is narrowly tailored to serve a compelling government interest. *See Adarand*, 515 U.S. at 237. With respect to tailoring the provision, we note that the provision is less narrowly tailored than the existing law that it would replace. *See* 42 U.S.C. § 6063(d) (“The consumer advisory committee shall reflect the racial and ethnic diversity of the geographic area served by the [Center].”). We also note that if the provision were rewritten to require the advisory committee to “reflect the demographic diversity” of the state or area served by the program, such a provision likely would not trigger strict scrutiny.

Native American concerns

¹ Alternatively, if section 204(e)(3) were interpreted to mean that racial and ethnic minorities automatically qualify, but that the phrase “attempt” refers to outreach efforts rather than the provision of direct benefits to such populations, then section 204(e)(3) would not be subject to the *Adarand* standard. *See* Memorandum for General Counsels, from Walter Dellinger, Assistant Attorney General, Office of Legal Counsel, Re: Legal Guidance on the Implications of the Supreme Court’s Decision in *Adarand Constructors Inc. v. Peña* at 9 (Jun. 28, 1995). But if section 204(e)(3) means that racial and ethnic minorities automatically qualify and “attempt” means the provision of benefits, then the section likely would be subject to the *Adarand* standard.

This bill would provide grants to states to develop programs to improve the quality of life of persons with developmental disabilities. It provides, however, no analogous opportunity for Indian tribes to participate in these programs. DOJ is committed to tribal self-determination and to promoting government-to-government relations with tribes. One facet of this is to ensure that tribes have an opportunity to participate, on similar footing as states, in federal programs that provide grants to states to pursue federal program goals. This provides a variety of benefits -- it promotes government-to-government relations, and the US has generally found that tribes are best able to judge the needs of their communities and how to meet them. In addition, relying on states to provide services in tribal areas has often proven problematic -- states are often reluctant to provide services in tribal areas, sometimes claiming this is a federal responsibility, or states may use their ability to provide services as a playing piece in unrelated tribal-state disputes. For this reason, the bill should be amended to include appropriate provisions allowing tribes to receive direct grants from the federal government to pursue the goals promoted by this bill.

The only provision for tribes is in section 142(a)(6), which authorizes technical assistance grants for American Indian Consortia, to pursue the advocacy programs in subtitle D. The definition of American Indian Consortium, however, limits the character of those entities to those with more than 150,000 members and contiguous land base in 2 or more states. That definition limits this program to only the Navajo Nation and any tribe or tribes with which it elects to set up a consortia. This program should be broadened to include individual tribes and consortia of tribes (more broadly defined to include any tribally-authorized consortia of one or more tribes), on a competitive basis. In addition, section 143(b) provides that with respect to consortia, the tribal council that authorizes the consortium shall act as the state. This provision is confusing because consortia will, by definition, have more than one authorizing tribal council. The provision should instead provide for agreement between the tribes as to how this responsibility will be allocated.

Andrea Kane

Record Type: Record

To: Christina S. Ho/OPD/EOP@EOP

cc:

Subject: Re: DOJ concerns with the Developmental Disabilities Act - H.R. 4920 (S. 1809)

----- Forwarded by Andrea Kane/OPD/EOP on 09/26/2000 08:45 AM -----



Mary L. Smith
09/25/2000 10:11:04 PM

Record Type: Record

To: See the distribution list at the bottom of this message

cc:

Subject: Re: DOJ concerns with the Developmental Disabilities Act - H.R. 4920 (S. 1809)

We wanted to have a conference call at 11am on Tuesday, September 26 to discuss this bill and its Senate companion S. 1809. It has already passed the House and is expected to be taken up by UC in the Senate shortly. Karen and Ingrid will email the conference line and code. Thanks, Mary

----- Forwarded by Mary L. Smith/WHO/EOP on 09/25/2000 10:08 PM -----

From: Karen N. Blank on 09/25/2000 10:53:39 AM

Record Type: Record

To: Michelle M. Aronowitz/WHO/EOP@EOP, Mary L. Smith/WHO/EOP@EOP

cc: Brian S. Mason/WHO/EOP@EOP, Andrew J. Scott/OMB/EOP@EOP, Eric W. Hunn/OMB/EOP@EOP, Ingrid M. Schroeder/OMB/EOP@EOP

Subject: Re: DOJ concerns with the Developmental Disabilities Act - H.R. 4920 (S. 1809)

FYI from DOJ - if the bill were enacted in its current form, Justice would **not** recommend veto but may want to do a signing statement that addresses its concerns.

----- Forwarded by Karen N. Blank/OMB/EOP on 09/25/2000 10:40 AM -----



"Taylor, Velma" <Velma.Taylor@usdoj.gov>
09/25/2000 10:19:34 AM

Record Type: Record

To: Karen N. Blank/OMB/EOP

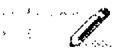
cc:
Subject: FW: DOJ concerns on H.R. 4920 are attached.

See DOJ's response below.

-----Original Message-----
From: Huntington, Clare
Sent: Monday, September 25, 2000 9:53 AM
To: Taylor, Velma
Subject: RE: DOJ concerns on H.R. 4920 are attached.

We would not recommend a veto but may recommend language for a signing statement. Also, if this is going to be sent to the Hill, or if there's time to change the memo before it's circulated within the Executive Branch, the quote in the first paragraph of the "Constitutional Concerns" section should read as follows: "the term 'unserved and underserved' includes populations such as individuals from racial and ethnic minority backgrounds" Thus, the two changes are putting "unserved and underserved" in single quotes, and adding "as individuals from racial and ethnic minority backgrounds." This latter change is important b/c it sets up the rest of the comment. Thanks so much.

----- Forwarded by Karen N. Blank/OMB/EOP on 09/25/2000 10:43 AM -----

 Mary L. Smith
09/23/2000 04:54:08 AM

Record Type: Record

To: Karen N. Blank/OMB/EOP@EOP
cc: michelle m. aronowitz/who/eop@eop, mary l. smith/who/eop@eop
bcc:
Subject: Re: DOJ concerns on H.R. 4920 are attached. 

I agree with Justice on the Native American parts of this bill -we shouldn't have agreed to the Senate version. Who is the sponsor of this bill?
From: Karen N. Blank on 09/22/2000 03:42:38 PM

From: Karen N. Blank on 09/22/2000 03:42:38 PM
Record Type: Record

To: Michelle M. Aronowitz/WHO/EOP@EOP
cc: mary l. smith/who/eop@eop
bcc:
Subject: Re: DOJ concerns on H.R. 4920 are attached. 

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S1809introduced.p

Michelle M. Aronowitz



Michelle M. Aronowitz
09/22/2000 03:05:06 PM

Record Type: Record

To: Karen N. Blank/OMB/EOP@EOP
cc: Mary L. Smith/WHO/EOP@EOP
bcc:
Subject: Re: DOJ concerns on H.R. 4920 are attached.

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With respect to the constitutional issues, I've reviewed them and don't see in them a reason not to support the bill. The first two points go to implementation by the Secretary, not the facial validity of the bill. With respect to the third point, even if a court does ultimately decide that the provision triggers strict scrutiny (which is arguable), it is still legally defensible under strict scrutiny and consistent with administration policy.

do you know if the provisions re: native americans are identical to current law and/or the senate version that we supported?

From: Karen N. Blank on 09/22/2000 02:49:25 PM

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Record Type: Record

To: Michelle M. Aronowitz/WHO/EOP@EOP
cc:
Subject: DOJ concerns on H.R. 4920 are attached.

are these similar to what you rec'd from Justice?

----- Forwarded by Karen N. Blank/OMB/EOP on 09/22/2000 02:54 PM -----



"Taylor, Velma" <Velma.Taylor@usdoj.gov>
09/22/2000 02:23:27 PM

Record Type: Record

To: Karen N. Blank/OMB/EOP

cc:

Subject: DOJ concerns on H.R. 4920 are attached.



- hr4920.omb.wpd

Message Sent To:

Joel K. Wiginton/WHO/EOP@EOP
Andrea Kane/OPD/EOP@EOP
Michelle M. Aronowitz/WHO/EOP@EOP
Karen N. Blank/OMB/EOP@EOP
Ingrid M. Schroeder/OMB/EOP@EOP
Lynn G. Cutler/WHO/EOP@EOP
Mark D. Magana/WHO/EOP@EOP
Cameron N. Cohen/WHO/EOP@EOP
Heather H. Howard/OPD/EOP@EOP

Andrea Kane

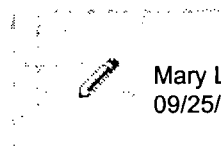
Record Type: Record

To: Christina S. Ho/OPD/EOP@EOP

cc:

Subject: Re: DOJ concerns on H.R. 4920 are attached.

----- Forwarded by Andrea Kane/OPD/EOP on 09/25/2000 09:29 PM -----



Mary L. Smith
09/25/2000 07:56:44 PM

Record Type: Record

To: Andrea Kane/OPD/EOP@EOP

cc:

Subject: Re: DOJ concerns on H.R. 4920 are attached.

----- Forwarded by Mary L. Smith/WHO/EOP on 09/25/2000 07:56 PM -----

From: Karen N. Blank on 09/25/2000 09:39:15 AM

Record Type: Record

To: Mary L. Smith/WHO/EOP@EOP

cc: michelle m. aronowitz/who/eop@eop

bcc:

Subject: Re: DOJ concerns on H.R. 4920 are attached. 

The sponsor of S. 1809 is Sen. Jeffords. The sponsor of HR 4920 is Rep. Lazio.
Mary L. Smith



Mary L. Smith
09/23/2000 04:54:08 AM

Record Type: Record

To: Karen N. Blank/OMB/EOP@EOP

cc: michelle m. aronowitz/who/eop@eop, mary l. smith/who/eop@eop

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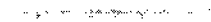
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S1809introduced.p

Michelle M. Aronowitz





Michelle M. Aronowitz
09/22/2000 03:05:06 PM

Record Type: Record

To: Karen N. Blank/OMB/EOP@EOP

cc: Mary L. Smith/WHO/EOP@EOP

bcc:

Subject: Re: DOJ concerns on H.R. 4920 are attached. 

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"Taylor, Velma" <Velma.Taylor@usdoj.gov>

09/22/2000 02:23:27 PM

Record Type: Record

To: Karen N. Blank/OMB/EOP

cc:

Subject: DOJ concerns on H.R. 4920 are attached.



- hr4920.omb.wpd

Andrea Kane

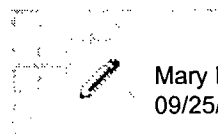
Record Type: Record

To: Christina S. Ho/OPD/EOP@EOP

cc:

Subject: Re: DOJ concerns on H.R. 4920 are attached.

----- Forwarded by Andrea Kane/OPD/EOP on 09/25/2000 09:29 PM -----



Mary L. Smith
09/25/2000 07:58:53 PM

Record Type: Record

To: Andrea Kane/OPD/EOP@EOP

cc:

Subject: Re: DOJ concerns on H.R. 4920 are attached.

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cc: mary l. smith/who/eop@eop

bcc:

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- hr4920.omb.wpd

HR 4920 / S. 1809

62240

- 4:50 at Perry's
- tomorrow → Departive Statement
- Th. + Fri. → education
- → legal mining (census data)
- Older Americans
- China Bill signing → 10/5

passed House
+ put on calendar in Senate, so
could come up at any time under U.S.

Reauthorization Bill

Jack Smaligan

Inconsistent w/ tribal policy of the Administration

- like to give tribes same ~~as~~ opp. as states

- def'n of ^{tribal} consortium (excludes everyone except Navajo).

→ ~ a setaside for university affiliated programs

~ a setaside for projects of Nat'l significance

Get TA → to Senate to the tribal
lang.

Must change the consortium
definition.

A version of the bill did pass the Senate
last year.

privacy → State can act on behalf ^{get access to medical records}
of DD person if guardian
is not doing a good job.

~~from~~

Title 3 → grants to train workers
everything else is strictly reauthorization

Mainly
Amy Lockhart HHS leg - 690-6311