TITLE 42 - THE PUBLIC HEALTH AND WELFARE
CHAPTER 144—DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS

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TITLE 42 - THE PUBLIC HEALTH AND WELFARE
CHAPTER 144 - DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS
SUBCHAPTER I - PROGRAMS FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

Part A - General Provisions
§ 15001. Findings, purposes, and policy
§ 15002. Definitions
§ 15003. Records and audits
§ 15004. Responsibilities of the Secretary
§ 15005. Reports of the Secretary
§ 15006. State control of operations
§ 15007. Employment of individuals with disabilities
§ 15008. Construction
§ 15009. Rights of individuals with developmental disabilities

Part B - Federal Assistance to State Councils on Developmental Disabilities
§ 15021. Purpose
§ 15022. State allotments
§ 15023. Payments to the States for planning, administration, and services
§ 15024. State plan
§ 15025. State Councils on Developmental Disabilities and designated State agencies
§ 15026. Federal and non-Federal share
§ 15027. Withholding of payments for planning, administration, and services
§ 15028. Appeals by States
§ 15029. Authorization of appropriations

Part C - Protection and Advocacy of Individual Rights
§ 15041. Purpose
§ 15042. Allotments and payments
§ 15043. System required
§ 15044. Administration
§ 15045. Authorization of appropriations

Part D - National Network of University Centers for Excellence in Developmental Disabilities Education, Research, and Service
§ 15061. Grant authority
§ 15062. Grant awards
§ 15063. Purpose and scope of activities
§ 15064. Applications
§ 15065. Definition
§ 15066. Authorization of appropriations

Part E - Projects of National Significance
§ 15081. Purpose
§ 15082. Grant authority
§ 15083. Authorization of appropriations

SUBCHAPTER II - FAMILY SUPPORT
§ 15091. Findings, purposes, and policy
§ 15092. Definitions and special rule
§ 15093. Grants to States
§ 15094. Application
§ 15095. Designation of the lead entity 66
§ 15096. Authorized activities 66
§ 15097. Reporting 67
§ 15098. Technical assistance 67
§ 15099. Evaluation 67
§ 15100. Projects of national significance 68
§ 15101. Authorization of appropriations 68

SUBCHAPTER III - PROGRAM FOR DIRECT SUPPORT WORKERS WHO ASSIST
INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES 70
§ 15111. Findings 70
§ 15112. Definitions 70
§ 15113. Reaching up scholarship program 70
§ 15114. Staff development curriculum authorization 71
§ 15115. Authorization of appropriations 73
TITLE 42—THE PUBLIC HEALTH AND WELFARE

Chap. ...Sec.
1. The Public Health Service [Mostly Repealed or Omitted, See Chapter 6A] ...1
1A. The Public Health Service; Supplemental Provisions [Transferred or Omitted] ...71
2. Sanitation and Quarantine ...81
3. Leprosy [Repealed] ...121
3A. Cancer [Repealed] ...137
4. Viruses, Serums, Toxins, Antitoxins, etc. [Repealed] ...141
5. Maternity and Infancy Welfare and Hygiene [Repealed] ...161
6. The Children’s Bureau ...191
6A. Public Health Service ...201
7. Social Security ...301
7A. Temporary Unemployment Compensation Program [Omitted] ...1400
8. Low-Income Housing ...1401
8A. Slum Clearance, Urban Renewal, and Farm Housing ...1441
8B. Public Works or Facilities [Omitted] ...1491
8C. Open-Space Land [Omitted or Repealed] ...1500
9. Housing of Persons Engaged in National Defense ...1501
10. Federal Security Agency [Transferred or Omitted] ...1601
11. Compensation for Disability or Death to Persons Employed at Military, Air, and Naval Bases Outside United States ...1651
12. Compensation for Injury, Death, or Detention of Employees of Contractors with United States Outside United States ...1701
13. School Lunch Programs ...1751
13A. Child Nutrition ...1771
14. Development and Control of Atomic Energy [Transferred to Chapter 23] ...1801
15. Disaster Relief [Repealed] ...1851
15A. Reciprocal Fire Protection Agreements ...1856
15B. Air Pollution Control [Transferred or Repealed] ...1857
16. National Science Foundation ...1861
16A. Grants for Support of Scientific Research [Repealed] ...1891
16B. Contracts for Scientific and Technological Research ...1900
17. Federal Employment Service [Transferred] ...1901
18. Youth Medals ...1921
19. Saline and Salt Waters [Repealed, Omitted, or Transferred] ...1951
19A. Water Resources Research Program [Repealed] ...1961
19B. Water Resources Planning ...1962
20. Elective Franchise ...1971
20A. Civil Rights Commission ...1975
21. Civil Rights ...1981
21A. Privacy Protection ...2000aa
21B. Religious Freedom Restoration ...2000bb
21C. Protection of Religious Exercise in Land Use and by Institutionalized Persons ...2000cc
21D. Detainee Treatment ...2000dd
21E. Privacy and Civil Liberties Protection and Oversight ...2000ee
21F. Prohibiting Employment Discrimination on the Basis of Genetic Information ...2000ff
22. Indian Hospitals and Health Facilities ...2001
23. Development and Control of Atomic Energy ...2011
24. Disposal of Atomic Energy Communities ...2301
25. Federal Flood Insurance ...2401
26. National Space Program [Repealed, Omitted, or Transferred] ...2451
26A. National Space Grant College and Fellowship Program [Repealed or Transferred] ...2486
26B. Biomedical Research in Space [Repealed or Transferred] ...2487
27. Loan Service of Captioned Films and Educational Media for Handicapped ...2491
28. Area Redevelopment Program [Omitted or Repealed] ...2501
29. Juvenile Delinquency and Youth Offenses Control [Omitted] ...2541
30. Manpower Development and Training Program [Repealed] ...2571
31. Public Works Acceleration Program ...2641
32. Third Party Liability for Hospital and Medical Care ...2651
33. Community Mental Health Centers [Omitted, Transferred, or Repealed] ...2661
34. Economic Opportunity Program ...2701
35. Programs for Older Americans ...3001
35A. Community Service Employment for Older Americans [Repealed] ...3061
36. Compensation of Condemnees in Development Programs [Repealed] ...3071
37. Community Facilities and Advance Land Acquisition ...3101
38. Public Works and Economic Development ...3121
39. Solid Waste Disposal [Omitted or Repealed, See Chapter 82] ...3251
40. Soil Information Assistance for Community Planning and Resource Development ...3271
41. Demonstration Cities and Metropolitan Development Program ...3301
42. Narcotic Addict Rehabilitation ...3401
43. Department of Health and Human Services ...3501
44. Department of Housing and Urban Development ...3531
45. Fair Housing ...3601
46. Justice System Improvement ...3701
47. Juvenile Delinquency Prevention and Control [Omitted or Repealed] ...3801
48. Guarantees for Financing New Community Land Development [Repealed or Omitted] ...3901
49. National Housing Partnerships ...3931
50. National Flood Insurance ...4001
51. Design and Construction of Public Buildings To Accommodate Physically Handicapped ...4151
52. Intergovernmental Cooperation [Repealed, See Chapter 65 of Title 31] ...4201
52A. Joint Funding Simplification [Repealed] ...4251
53. Advisory Commission on Intergovernmental Relations ...4271
54. Cabinet Committee on Opportunities for Spanish-Speaking People [Omitted] ...4301
55. National Environmental Policy ...4321
56. Environmental Quality Improvement ...4371
57. Environmental Pollution Study ...4391
58. Disaster Relief [Repealed or Transferred] ...4401
59. National Urban Policy and New Community Development ...4501
60. Comprehensive Alcohol Abuse and Alcoholism Prevention, Treatment, and Rehabilitation Program ...4541
61. Uniform Relocation Assistance and Real Property Acquisition Policies for Federal and Federally Assisted Programs ...4601
62. Intergovernmental Personnel Program ...4701
63. Lead-Based Paint Poisoning Prevention ...4801
63A. Residential Lead-Based Paint Hazard Reduction ...4851
64. Public Service Employment Programs [Omitted] ...4871
65. Noise Control ...4901
66. Domestic Volunteer Services ...4950
67. Child Abuse Prevention and Treatment and Adoption Reform ...5101
68. Disaster Relief ...5121
69. Community Development ...5301
70. Manufactured Home Construction and Safety Standards ...5401
71. Solar Energy ...5501
72. Juvenile Justice and Delinquency Prevention ...5601
73. Development of Energy Sources ...5801
74. Nonnuclear Energy Research and Development ...5901
75. Programs for Individuals With Developmental Disabilities [Repealed] ...6000
76. Age Discrimination in Federally Assisted Programs ...6101
77. Energy Conservation ...6201
78. National Petroleum Reserve in Alaska ...6501
79. Science and Technology Policy, Organization and Priorities ...6601
80. Public Works Employment ...6701
81. Energy Conservation and Resource Renewal ...6801
82. Solid Waste Disposal ...6901
83. Energy Extension Service ...7001
84. Department of Energy ...7101
85. Air Pollution Prevention and Control ...7401
86. Earthquake Hazards Reduction ...7701
87. Water Research and Development [Repealed or Transferred] ...7801
88. Uranium Mill Tailings Radiation Control ...7901
89. Congregate Housing Services ...8001
90. Neighborhood and City Reinvestment, Self-Help and Revitalization ...8101
91. National Energy Conservation Policy ...8201
92. Powerplant and Industrial Fuel Use ...8301
93. Emergency Energy Conservation ...8501
94. Low-Income Energy Assistance ...8601
95. United States Synthetic Fuels Corporation [Omitted] ...8701
96. Biomass Energy and Alcohol Fuels ...8801
97. Acid Precipitation Program and Carbon Dioxide Study ...8901
98. Ocean Thermal Energy Conversion Research and Development ...9001
99. Ocean Thermal Energy Conversion ...9101
100. Wind Energy Systems ...9201
101. Magnetic Fusion Energy Engineering ...9301
102. Mental Health Systems ...9401
103. Comprehensive Environmental Response, Compensation, and Liability ...9601
104. Nuclear Safety Research, Development, and Demonstration ...9701
105. Community Services Programs ...9801
106. Community Services Block Grant Program ...9901
107. Consumer-Patient Radiation Health and Safety ...10001
108. Nuclear Waste Policy ...10101
109. Water Resources Research ...10301
109A. Membrane Processes Research ...10341
109B. Secure Water ...10361
110. Family Violence Prevention and Services ...10401
111. Emergency Federal Law Enforcement Assistance ...10501
112. Victim Compensation and Assistance ...10601
113. State Justice Institute ...10701
114. Protection and Advocacy for Individuals With Mental Illness ...10801
115. Child Development Associate Scholarship Assistance Program ...10901
116. Emergency Planning and Community Right-To-Know ...11001
117. Encouraging Good Faith Professional Review Activities ...11101
118. Alzheimer’s Disease and Related Dementias Research ...11201
119. Homeless Assistance ...11301
120. Enterprise Zone Development ...11501
121. International Child Abduction Remedies ...11601
122. Native Hawaiian Health Care ...11701
123. Drug Abuse Education and Prevention ...11801
124. Public Housing Drug Elimination ...11901
125. Renewable Energy and Energy Efficiency Technology Competitiveness ...12001
126. Equal Opportunity for Individuals With Disabilities ...12101
127. Coordinated Services for Children, Youth, and Families ...12301
128. Hydrogen Research, Development, and Demonstration Program ...12401
129. National and Community Service ...12501
130. National Affordable Housing ...12701
131. Housing Opportunities for Persons With AIDS ...12901
132. Victims of Child Abuse ...13001
133. Pollution Prevention ...13101
134. Energy Policy ...13201
135. Residency and Service Requirements in Federally Assisted Housing ...13601
136. Violent Crime Control and Law Enforcement ...13701
137. Management of Rechargeable Batteries and Batteries Containing Mercury ...14301
138. Assisted Suicide Funding Restriction ...14401
139. Volunteer Protection ...14501
140. Criminal Justice Identification, Information, and Communication ...14601
140A. Jennifer’s Law ...14661
141. Commercial Space Opportunities and Transportation Services [Repealed or Transferred] ...14701
142. Poison Control Center Enhancement and Awareness [Repealed] ...14801
143. Intercountry Adoptions ...14901
144. Developmental Disabilities Assistance and Bill of Rights ...15001
145. Public Safety Officer Medal of Valor and Tributes ...15201
145A. Law Enforcement Congressional Badge of Bravery ...15231
146. Election Administration Improvement ...15301
147. Prison Rape Elimination ...15601
148. Windstorm Impact Reduction ...15701
149. National Energy Policy and Programs ...15801
150. National Aeronautics and Space Programs, 2005 [Repealed, Omitted, or Transferred] ...16601
151. Child Protection and Safety  ...16901
152. Energy Independence and Security  ...17001
153. Community Safety Through Recidivism Prevention  ...17501
154. Combating Child Exploitation  ...17601
155. Aeronautics and Space Activities [Repealed, Omitted, or Transferred]  ...17701
156. Health Information Technology  ...17901
157. Quality, Affordable Health Care for All Americans  ...18001
158. Support for Pregnant and Parenting Teens and Women  ...18201
159. Space Exploration, Technology, and Science  ...18301
CHAPTER 144—DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS

SUBCHAPTER I—PROGRAMS FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

Part A—General Provisions
Sec.
15001. Findings, purposes, and policy.
15002. Definitions.
15003. Records and audits.
15004. Responsibilities of the Secretary.
15005. Reports of the Secretary.
15006. State control of operations.
15007. Employment of individuals with disabilities.
15008. Construction.
15009. Rights of individuals with developmental disabilities.

Part B—Federal Assistance to State Councils on Developmental Disabilities
15021. Purpose.
15022. State allotments.
15023. Payments to the States for planning, administration, and services.
15024. State plan.
15025. State Councils on Developmental Disabilities and designated State agencies.
15026. Federal and non-Federal share.
15027. Withholding of payments for planning, administration, and services.
15028. Appeals by States.
15029. Authorization of appropriations.

Part C—Protection and Advocacy of Individual Rights
15041. Purpose.
15042. Allotments and payments.
15043. System required.
15044. Administration.
15045. Authorization of appropriations.

Part D—National Network of University Centers for Excellence in Developmental Disabilities Education, Research, and Service
15061. Grant authority.
15062. Grant awards.
15063. Purpose and scope of activities.
15064. Applications.
15065. Definition.
15066. Authorization of appropriations.

Part E—Projects of National Significance
15081. Purpose.
15082. Grant authority.
15083. Authorization of appropriations.

SUBCHAPTER II—FAMILY SUPPORT
15091. Findings, purposes, and policy.
15092. Definitions and special rule.
15093. Grants to States.
15094. Application.
15095. Designation of the lead entity.
15096. Authorized activities.
15097. Reporting.
15098. Technical assistance.
15099. Evaluation.
15100. Projects of national significance.
15101. Authorization of appropriations.

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

15111. Findings.
15112. Definitions.
15113. Reaching up scholarship program.
15114. Staff development curriculum authorization.
15115. Authorization of appropriations.
SUBCHAPTER I—PROGRAMS FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES
Part A—General Provisions

§ 15001. Findings, purposes, and policy

(a) Findings

Congress finds that—

(1) disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society;

(2) in 1999, there were 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 comprise 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 emphasis (as defined in section 15002 of this title);

(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 developmental disabilities and their families do not have access to appropriate support and services, including 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, individualized supports, and other forms of assistance, that are most effective when provided in a coordinated manner;

(8) there is a need to ensure that services, supports, and other assistance are provided in a culturally competent manner, that ensures that individuals from racial and ethnic minority backgrounds are fully included in all activities provided under this subchapter;

(9) family members, friends, and members of the community can play an important role in enhancing the lives of individuals with developmental disabilities, especially when the family members, friends, and community members are provided with the necessary community services, individualized 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 developmental disabilities are waiting for appropriate services in their communities, in the areas of emphasis;

(13) the public needs to be made more aware of the capabilities and competencies of individuals with developmental disabilities, particularly in cases in which the individuals are provided with necessary 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;
(15) there needs to be greater effort to recruit individuals from minority backgrounds into professions serving individuals with developmental disabilities 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—
   (A) make informed choices and decisions about their lives;
   (B) live in homes and communities in which such individuals can exercise their full rights and responsibilities as citizens;
   (C) pursue meaningful and productive lives;
   (D) contribute to their families, communities, and States, and the Nation;
   (E) have interdependent friendships and relationships with other persons;
   (F) live free of abuse, neglect, financial and sexual exploitation, and violations of their legal and human rights; and
   (G) achieve full integration and inclusion in society, in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of each individual; and

(17) as the Nation, States, and communities maintain and expand community living options for individuals with developmental disabilities, there is a need to evaluate the access to those options by individuals with developmental disabilities and the effects of those options on individuals with developmental disabilities.

(b) Purpose

The purpose of this subchapter is to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life, through culturally competent programs authorized under this subchapter, including specifically—

(1) State Councils on Developmental Disabilities in each State to engage in advocacy, capacity building, and systemic change activities that—
   (A) are consistent with the purpose described in this subsection and the policy described in subsection (c) of this section; and
   (B) contribute to a coordinated, consumer- and 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;

(2) protection and advocacy systems in each State to protect the legal and human rights of individuals with developmental disabilities;

(3) University Centers for Excellence in Developmental Disabilities Education, Research, and Service—
   (A) to provide interdisciplinary pre-service preparation and continuing education of students and fellows, which may include the preparation and continuing education of leadership, direct service, clinical, or other personnel to strengthen and increase the capacity of States and communities to achieve the purpose of this subchapter;
   (B) to provide community services—
      (i) that provide training and technical assistance for individuals with developmental disabilities, their families, professionals, paraprofessionals, policymakers, students, and other members of the community; and
      (ii) that may provide services, supports, and assistance for the persons described in clause (i) through demonstration and model activities;
(C) to conduct research, which may include basic or applied research, evaluation, and the analysis of public policy in areas that affect or could affect, either positively or negatively, individuals with developmental disabilities and their families; and

(D) to disseminate information related to activities undertaken to address the purpose of this subchapter, especially dissemination of information that demonstrates that the network authorized under this part is a national and international resource that includes specific substantive areas of expertise that may be accessed and applied in diverse settings and circumstances; and

(4) funding for—

(A) national initiatives to collect necessary data on issues that are directly or indirectly relevant to the lives of individuals with developmental 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) of this section; and

(C) other nationally significant activities.

(c) Policy

It is the policy of the United States that all programs, projects, and activities receiving assistance under this subchapter shall be carried out in a manner consistent with the principles that—

(1) individuals with developmental disabilities, including those with the most severe developmental disabilities, are capable of self-determination, independence, productivity, and integration and inclusion in all facets of community life, but often require the provision of community services, individualized supports, and other forms of assistance;

(2) individuals with developmental disabilities and their families have competencies, capabilities, and personal goals that should be recognized, supported, and encouraged, and any assistance to such individuals should be provided in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities 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 programs that affect the lives of such individuals and their families;

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

(5) specific efforts must be made to ensure that individuals with developmental disabilities from racial and ethnic minority backgrounds and their families enjoy increased and meaningful opportunities to access and use community services, individualized supports, and other forms of assistance available to other individuals with developmental disabilities and their families;

(6) recruitment efforts in disciplines related to developmental disabilities relating to pre-service training, community training, practice, administration, and policymaking must focus on bringing larger numbers of racial and ethnic minorities into the disciplines in order to provide appropriate skills, knowledge, role models, and sufficient personnel to address the growing needs of an increasingly diverse population;

(7) with education and support, communities can be accessible to and responsive to the needs of individuals with developmental disabilities and their families and are enriched by full and active participation in community activities, and contributions, by individuals with developmental disabilities and their families;

(8) individuals with developmental disabilities have access to opportunities and the necessary support to be included in community life, have interdependent relationships, live in homes and communities, and make contributions to their families, communities, and States, and the Nation;
(9) efforts undertaken to maintain or expand community-based living options for individuals with disabilities should be monitored in order to determine and report to appropriate individuals and entities the extent of access by individuals with developmental disabilities to those options and the extent of compliance by entities providing those options with 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 after-school 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 transportation, in order to be independent and directly contribute to and participate in all facets of community life; and
(12) individuals with developmental disabilities need to have access to and use of recreational, leisure, and social opportunities in the most integrated settings, in order to enrich their participation in community life.


**Short Title**


**Special Olympics Sport and Empowerment**


“SECTION 1. SHORT TITLE.

“This Act may be cited as the ‘Special Olympics Sport and Empowerment Act of 2004’.

“SEC. 2. FINDINGS AND PURPOSE.

“(a) Findings.—Congress finds the following:

“(1) Special Olympics celebrates the possibilities of a world where everybody matters, everybody counts, every person has value, and every person has worth.

“(2) The Government and the people of the United States recognize the dignity and value the giftedness of children and adults with an intellectual disability.

“(3) The Government and the people of the United States are determined to end the isolation and stigmatization of people with an intellectual disability.

“(4) For more than 36 years, Special Olympics has encouraged skill, sharing, courage, and joy through year-round sports training and athletic competition for children and adults with intellectual disabilities.

“(5) Special Olympics provides year-round sports training and competitive opportunities to 1,500,000 athletes with intellectual disabilities in 26 sports and plans to expand the joy of participation through sport to hundreds of thousands of people with intellectual disabilities within the United States and worldwide over the next 5 years.

“(6) Special Olympics has demonstrated its ability to provide a major positive effect on the quality of life of people with intellectual disabilities, improving their health and physical well-being, building their confidence and self-esteem, and giving them a voice to become active and productive members of their communities.

“(7) In society as a whole, Special Olympics has become a vehicle and platform for breaking down artificial barriers, improving public health, changing negative attitudes in education, and helping athletes overcome the prejudice that people with intellectual disabilities face in too many places.

“(8) The Government of the United States enthusiastically supports Special Olympics, recognizes its importance in improving the lives of people with intellectual disabilities, and recognizes Special Olympics as a valued and important component of the global community.

“(b) Purpose.—The purposes of this Act are to—
“(1) provide support to Special Olympics to increase athlete participation in and public awareness about the Special Olympics movement;
“(2) dispel negative stereotypes about people with intellectual disabilities;
“(3) build athletic and family involvement through sport; and
“(4) promote the extraordinary gifts of people with intellectual disabilities.

SEC. 3. ASSISTANCE FOR SPECIAL OLYMPICS.

“(a) Education Activities.—The Secretary of Education may award grants to, or enter into contracts or cooperative agreements with, Special Olympics to carry out the following:
“(1) Activities to promote the expansion of Special Olympics, including activities to increase the participation of individuals with intellectual disabilities within the United States.
“(2) The design and implementation of Special Olympics education programs, including character education and volunteer programs that support the purposes of this Act, that can be integrated into classroom instruction and are consistent with academic content standards.
“(b) International Activities.—The Secretary of State may award grants to, or enter into contracts or cooperative agreements with, Special Olympics to carry out the following:
“(1) Activities to increase the participation of individuals with intellectual disabilities in Special Olympics outside of the United States.
“(2) Activities to improve the awareness outside of the United States of the abilities and unique contributions that individuals with intellectual disabilities can make to society.
“(c) Healthy Athletes.—
“(1) In general.—The Secretary of Health and Human Services may award grants to, or enter into contracts or cooperative agreements with, Special Olympics for the implementation of on-site health assessments, screening for health problems, health education, data collection, and referrals to direct health care services.
“(2) Coordination.—Activities under paragraph (1) shall be coordinated with private health providers, existing authorized programs of State and local jurisdictions, or the Department of Health and Human Services, as applicable.
“(d) Limitation.—Amounts appropriated to carry out this section shall not be used for direct treatment of diseases, medical conditions, or mental health conditions. Nothing in the preceding sentence shall be construed to limit the use of non-Federal funds by Special Olympics.

SEC. 4. APPLICATION AND ANNUAL REPORT.

“(a) Application.—
“(1) In general.—To be eligible for a grant, contract, or cooperative agreement under subsection (a), (b), or (c) of section 3, Special Olympics shall submit an application at such time, in such manner, and containing such information as the Secretary of Education, Secretary of State, or Secretary of Health and Human Services, as applicable, may require.
“(2) Content.—At a minimum, an application under this subsection shall contain the following:
“(A) Activities.—A description of activities to be carried out with the grant, contract, or cooperative agreement.
“(B) Measurable goals.—Information on specific measurable goals and objectives to be achieved through activities carried out with the grant, contract, or cooperative agreement.

“(b) Annual Report.—
“(1) In general.—As a condition on receipt of any funds under subsection (a), (b), or (c) of section 3, Special Olympics shall agree to submit an annual report at such time, in such manner, and containing such information as the Secretary of Education, Secretary of State, or Secretary of Health and Human Services, as applicable, may require.
“(2) Content.—At a minimum, each annual report under this subsection shall describe the degree to which progress has been made toward meeting the goals and objectives described in the applications submitted under subsection (a).

SEC. 5. AUTHORIZATION OF APPROPRIATIONS.

There are authorized to be appropriated—

“(1) for grants, contracts, or cooperative agreements under section 3 (a), $5,500,000 for fiscal year 2005, and such sums as may be necessary for each of the 4 succeeding fiscal years;
“(2) for grants, contracts, or cooperative agreements under section 3 (b), $3,500,000 for fiscal year 2005, and such
sums as may be necessary for each of the 4 succeeding fiscal years; and

“(3) for grants, contracts, or cooperative agreements under section 3 (c), $6,000,000 for each of fiscal years 2005
through 2009.”

Ex. Ord. No. 12994. President’s Committee on Mental Retardation

Ex. Ord. No. 13446, § 5, Sept. 28, 2007, 72 F.R. 56176, provided:

By the authority vested in me as President by the Constitution and the laws of the United States of America, and in
order to promote full participation of people with intellectual disabilities in their communities, it is hereby ordered
as follows:

Section 1. Committee Continued and Responsibilities Expanded. The President’s Committee on Mental Retardation,
with expanded membership and expanded responsibilities, and renamed the President’s Committee for People with
Intellectual Disabilities (Committee), is hereby continued in operation.

Sec. 2. Composition of Committee. (a) The Committee shall be composed of the following members:

(1) The Attorney General;
(2) The Secretary of the Interior;
(3) The Secretary of Commerce;
(4) The Secretary of Labor;
(5) The Secretary of Health and Human Services;
(6) The Secretary of Housing and Urban Development;
(7) The Secretary of Transportation;
(8) The Secretary of Education;
(9) The Secretary of Homeland Security;
(10) The Chief Executive Officer of the Corporation for National and Community Service;
(11) The Commissioner of Social Security;
(12) The Chairman of the Equal Employment Opportunity Commission;
(13) The Chairperson of the National Council on Disability; and

(14) No more than 21 other members who shall be appointed to the Committee by the President. These citizen members
shall consist of individuals who represent a broad spectrum of perspectives, experience, and expertise on intellectual
disabilities; persons with intellectual disabilities and members of families with a child or adult with intellectual
disabilities; and persons employed in either the public or the private sector. Except as the President may from time
to time otherwise direct, appointees under this paragraph shall serve for two-year terms, except that an appointment
made to fill a vacancy occurring before the expiration of a term shall be made for the balance of the unexpired term.

(b) The President shall designate the Chair of the Committee from the 21 citizen members. The Chair shall preside
over meetings of the Committee and represent the Committee on appropriate occasions.

Sec. 3. Functions of the Committee. (a) Consistent with subsection (c) of this section, the Committee shall:

(1) provide such advice concerning intellectual disabilities as the President or the Secretary of Health and Human
Services may request; and
(2) provide advice to the President concerning the following for people with intellectual disabilities:
(A) expansion of educational opportunities;
(B) promotion of homeownership;
(C) assurance of workplace integration;
(D) improvement of transportation options;
(E) expansion of full access to community living; and
(F) increasing access to assistive and universally designed technologies.
(b) The Committee shall provide an annual report to the President through the Secretary of Health and Human Services. Such additional reports may be made as the President may direct or as the Committee may deem appropriate.

(c) The members shall advise the President and carry out their advisory role consistent with the requirements of the Federal Advisory Committee Act, as amended (5 U.S.C. App.).

Sec. 4. Cooperation by Agencies. The heads of Federal departments and agencies shall:

(a) designate, when requested by the Secretary of Health and Human Services, an officer or employee of such department or agency to serve as a liaison with the Committee; and

(b) furnish such information and assistance to the Committee, to the extent permitted by law, as the Secretary of Health and Human Services may request to assist the Committee in performing its functions under this order.

Sec. 5. Administration. (a) The Department of Health and Human Services shall provide the Committee with necessary staff support, administrative services and facilities, and funding, to the extent permitted by law.

(b) Each member of the Committee, except any member who receives other compensation from the United States Government, may receive compensation for each day engaged in the work of the Committee, as authorized by law (5 U.S.C. 3109), and may also receive travel expenses, including per diem in lieu of subsistence, as authorized by law (5 U.S.C. 5701–5707), for persons employed intermittently in the Government service. Committee members with disabilities may be compensated for attendant expenses, consistent with Government procedures and practices.

(c) The Secretary of Health and Human Services shall perform such other functions with respect to the Committee as may be required by the Federal Advisory Committee Act, as amended (5 U.S.C. App.), except that of reporting to the Congress.

Sec. 6. General. (a) Nothing in this order shall be construed as subjecting any Federal agency, or any function vested by law in, or assigned pursuant to law to, any Federal agency, to the authority of the Committee or as abrogating or restricting any such function in any manner.

(b) This order is not intended to, and does not, create any right or benefit, substantive or procedural, enforceable at law or in equity by any party against the United States, its departments, agencies, instrumentalities, or entities, its officers or employees, or any other person.

**Extension of Term of President’s Committee for People with Intellectual Disabilities (formerly President’s Committee on Mental Retardation)**


Term of the President’s Committee on Mental Retardation extended until Sept. 30, 1984, by Ex. Ord. No. 12399, Dec. 31, 1982, 48 F.R. 379, formerly set out as a note under section 14 of the Federal Advisory Committee Act in the Appendix to Title 5.

Term of the President’s Committee on Mental Retardation extended until Sept. 30, 1985, by Ex. Ord. No. 12489, Sept. 28, 1984, 49 F.R. 38927, formerly set out as a note under section 14 of the Federal Advisory Committee Act in the Appendix to Title 5.

Term of the President’s Committee on Mental Retardation extended until Sept. 30, 1987, by Ex. Ord. No. 12534, Sept. 30, 1985, 50 F.R. 40319, formerly set out as a note under section 14 of the Federal Advisory Committee Act in the Appendix to Title 5.


Term of the President’s Committee on Mental Retardation extended until Sept. 30, 1991, by Ex. Ord. No. 12692, Sept. 29, 1989, 54 F.R. 40627, formerly set out as a note under section 14 of the Federal Advisory Committee Act in the Appendix to Title 5.

Term of the President’s Committee on Mental Retardation extended until Sept. 30, 1993, by Ex. Ord. No. 12774, Sept. 27, 1991, 56 F.R. 49835, formerly set out as a note under section 14 of the Federal Advisory Committee Act in the Appendix to Title 5.

Term of the President’s Committee on Mental Retardation extended until Sept. 30, 1995, by Ex. Ord. No. 12869, Sept. 30, 1993, 58 F.R. 51751, formerly set out as a note under section 14 of the Federal Advisory Committee Act in the Appendix to Title 5.
§ 15002. Definitions

In this subchapter:

(1) **American Indian Consortium**

The term “American Indian Consortium” means any confederation of 2 or more recognized American Indian tribes, created through the official action of each participating tribe, that has a combined total resident population of 150,000 enrolled tribal members and a contiguous territory of Indian lands in 2 or 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, health-related activities, employment-related activities, housing-related activities, transportation-related activities, recreation-related activities, and other services available or offered to individuals in a community, including formal and informal community supports, that affect their quality of life.

(3) **Assistive technology device**

The term “assistive technology device” means any item, piece of equipment, or product system, whether acquired commercially, modified or customized, that is used to increase, maintain, or improve functional capabilities of individuals with developmental disabilities.

(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—
(A) conducting an evaluation of the needs of an individual with a developmental disability, including a functional evaluation of the individual in the individual’s customary environment;
(B) purchasing, leasing, or otherwise providing for the acquisition of an assistive technology device by an individual with a developmental disability;
(C) selecting, designing, fitting, customizing, adapting, applying, maintaining, repairing or replacing an assistive technology device;
(D) coordinating and using another therapy, intervention, or service with an assistive technology device, such as a therapy, intervention, or service associated with an education or rehabilitation plan or program;
(E) providing training or technical assistance for an individual with a developmental disability, or, where appropriate, a family member, guardian, advocate, or authorized representative of an individual with a developmental disability; and
(F) providing training or technical assistance for professionals (including individuals providing education and rehabilitation services), employers, or other individuals who provide services to, employ, or are otherwise substantially involved in the major life functions of, an individual with developmental disabilities.

(5) Center
The term “Center” means a University Center for Excellence in Developmental Disabilities Education, Research, and Service established under part D of this subchapter.

(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.

(7) Culturally competent
The term “culturally competent”, used with respect to services, supports, or other assistance, means services, supports, or other assistance that is conducted or provided in a manner that is responsive to the beliefs, interpersonal styles, attitudes, language, and behaviors of individuals who are receiving the services, supports, or other assistance, and in a manner that has the greatest likelihood of ensuring their maximum participation in the program involved.

(8) Developmental disability
(A) In general
The term “developmental disability” means a severe, chronic disability of an individual that—
(i) is attributable to a mental or physical impairment or combination of mental and physical impairments;
(ii) is manifested before the individual attains age 22;
(iii) is likely to continue indefinitely;
(iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:
   (I) Self-care.
   (II) Receptive and expressive language.
   (III) Learning.
   (IV) Mobility.
   (V) Self-direction.
   (VI) Capacity for independent living.
   (VII) Economic self-sufficiency; and
(v) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

(B) **Infants and young children**

An individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described in clauses (i) through (v) of subparagraph (A) if the individual, without services and supports, has a high probability of meeting those criteria later in life.

(9) **Early intervention activities**

The term “early intervention activities” means advocacy, capacity building, and systemic change activities provided to individuals described in paragraph (8)(B) and their families to enhance—

(A) the development of the individuals to maximize their potential; and

(B) the capacity of families to meet the special needs of the individuals.

(10) **Education activities**

The term “education activities” means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities being able to access 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

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

(B) **Specific services**

Such term includes respite care, provision of rehabilitation technology and assistive technology, personal assistance services, parent training and counseling, support for families headed by aging caregivers, vehicular and home modifications, and assistance with extraordinary expenses, associated with the needs of individuals with developmental 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, including assistance related to renting, owning, or modifying an apartment or home.

(15) **Inclusion**

The term “inclusion”, used with respect to individuals with developmental disabilities, means the acceptance and encouragement of the presence and participation of individuals with developmental disabilities, by individuals without disabilities, in social, educational, work, and community activities, that enables individuals with developmental disabilities to—

(A) have friendships and relationships with individuals and families of their own choice;
(B) live in homes close to community resources, with regular contact with individuals without disabilities in their communities;
(C) enjoy full access to and active participation in the same community activities and types of employment as individuals without disabilities; and
(D) take full advantage of their integration into the same community resources as individuals without disabilities, living, learning, working, and enjoying life in regular contact with individuals without disabilities.

(16) **Individualized supports**

The term “individualized supports” means supports that—

(A) enable an individual with a developmental disability to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life;
(B) are designed to—

(i) enable such individual to control such individual’s environment, permitting the most independent life possible;
(ii) prevent placement into a more restrictive living arrangement than is necessary; and
(iii) enable such individual to live, learn, work, and enjoy life in the community; and
(C) include—

(i) early intervention services;
(ii) respite care;
(iii) personal assistance services;
(iv) family support services;
(v) supported employment services;
(vi) support services for families headed by aging caregivers of individuals with developmental disabilities; and
(vii) provision of rehabilitation technology and assistive technology, and assistive technology services.

(17) **Integration**

The term “integration”, used with respect to individuals with developmental disabilities, means exercising the equal right of individuals with developmental disabilities to access and use the same community resources as are used by and available to other individuals.

(18) **Not-for-profit**

The term “not-for-profit”, used with respect to an agency, institution, or organization, means an agency, institution, or organization that is owned or operated by 1 or more corporations or associations, no part of the net earnings of which inures, or may lawfully inure, to the benefit of any private shareholder or individual.

(19) **Personal assistance services**

The term “personal assistance services” means a range of services, provided by 1 or more individuals, designed to assist an individual with a disability to perform daily activities, including activities on or
off a job that such individual would typically perform if such individual did not have a disability. Such services shall be designed to increase such individual’s control in life and ability to perform everyday activities, including activities on or off a job.

(20) **Prevention activities**

The term “prevention activities” means activities that address the causes of developmental disabilities and the exacerbation of functional limitation, such as activities that—

(A) eliminate or reduce the factors that cause or predispose individuals to developmental disabilities or that increase the prevalence of developmental disabilities;  
(B) increase the early identification of problems to eliminate circumstances that create or increase functional limitations; and  
(C) mitigate against the effects of developmental disabilities throughout the lifespan of an individual.

(21) **Productivity**

The term “productivity” means—

(A) engagement in income-producing work that is measured by increased income, improved 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 accordance with section 15043 of this title.

(23) **Quality assurance activities**

The term “quality assurance activities” means advocacy, capacity building, and systemic change activities that result in improved consumer- and family-centered quality assurance and that result in systems of quality assurance and consumer protection that—

(A) include monitoring of services, supports, and assistance provided to an individual with developmental disabilities that ensures that the individual—  
(i) will not experience abuse, neglect, sexual or financial exploitation, or violation of legal or human rights; and  
(ii) will not be subject to the inappropriate use of restraints or seclusion;  
(B) include training in leadership, self-advocacy, and self-determination for individuals with developmental disabilities, their families, and their guardians to ensure that those individuals—  
(i) will not experience abuse, neglect, sexual or financial exploitation, or violation of legal or human rights; and  
(ii) will not be subject to the inappropriate use of restraints or seclusion; or  
(C) include activities related to interagency coordination and systems integration that result in improved and enhanced services, supports, and other assistance that contribute to and protect the self-determination, independence, productivity, and integration and inclusion in all facets of community life, of individuals with developmental disabilities.

(24) **Recreation-related activities**

The term “recreation-related activities” means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities having access to and use of recreational, leisure, and social activities, in their communities.

(25) **Rehabilitation technology**

The term “rehabilitation technology” means the systematic application of technologies, engineering methodologies, or scientific principles to meet the needs of, and address the barriers confronted by, individuals with developmental disabilities in areas that include education, rehabilitation, employment,
transportation, independent living, and recreation. Such term includes rehabilitation engineering, and the provision of assistive technology devices and assistive technology services.

(26) **Secretary**

The term “Secretary” means the Secretary of Health and Human Services.

(27) **Self-determination activities**

The term “self-determination activities” means activities that result in individuals with developmental disabilities, with appropriate assistance, having—

(A) the ability and opportunity to communicate and make personal decisions;

(B) the ability and opportunity to communicate choices and exercise control over the type and intensity of services, supports, and other assistance the individuals receive;

(C) the authority to control resources to obtain needed services, supports, and other assistance;

(D) opportunities to participate in, and contribute to, their communities; and

(E) support, including financial support, to advocate for themselves and others, to develop leadership skills, through training in self-advocacy, to participate in coalitions, to educate policymakers, and to play a role in the development of public policies that affect individuals with developmental disabilities.

(28) **State**

The term “State”, except as otherwise provided, includes, in addition to each of the several States of the United States, the District of Columbia, the Commonwealth of Puerto Rico, the United States Virgin Islands, Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands.

(29) **State Council on Developmental Disabilities**

The term “State Council on Developmental Disabilities” means a Council established under section 15025 of this title.

(30) **Supported employment services**

The term “supported employment services” means services that enable individuals with developmental disabilities to perform competitive work in integrated work settings, in the case of individuals with developmental disabilities—

(A) (i) for whom competitive employment has not traditionally occurred; or

(ii) for whom competitive employment has been interrupted or intermittent as a result of significant disabilities; and

(B) who, because of the nature and severity of their disabilities, need intensive supported employment services or extended services in order to perform such work.

(31) **Transportation-related activities**

The term “transportation-related activities” means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities having access to and use of transportation.

(32) **Unserved and underserved**

The term “unserved and underserved” includes populations such as individuals from racial and ethnic minority backgrounds, disadvantaged individuals, individuals with limited English proficiency, individuals from underserved geographic areas (rural or urban), and specific groups of individuals within the population of individuals with developmental disabilities, including individuals who require assistive technology in order to participate in and contribute to community life.

§ 15003. Records and audits

(a) Records

Each recipient of assistance under this subchapter shall keep such records as the Secretary shall prescribe, including—

(1) records that fully disclose—

(A) the amount and disposition by such recipient of the assistance;

(B) the total cost of the project or undertaking in connection with which such assistance is given or used; and

(C) the amount of that portion of the cost of the project or undertaking that is supplied by other sources; and

(2) such other records as will facilitate an effective audit.

(b) Access

The Secretary and the Comptroller General of the United States, or any of their duly authorized representatives, shall have access for the purpose of audit and examination to any books, documents, papers, and records of the recipients of assistance under this subchapter that are pertinent to such assistance.


§ 15004. Responsibilities of the Secretary

(a) Program accountability

(1) In general

In order to monitor entities that received funds under this chapter to carry out activities under parts B, C, and D of this subchapter and determine the extent to which the entities have been responsive to the purpose of this subchapter and have taken actions consistent with the policy described in section 15001 (c) of this title, the Secretary shall develop and implement an accountability process as described in this subsection, with respect to activities conducted after October 1, 2001.

(2) Areas of emphasis

The Secretary shall develop a process for identifying and reporting (pursuant to section 15005 of this title) on progress achieved through advocacy, capacity building, and systemic change activities, undertaken by the entities described in paragraph (1), that resulted in individuals with developmental disabilities and their families participating in the design of and having access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life. Specifically, the Secretary shall develop a process for identifying and reporting on progress achieved, through advocacy, capacity building, and systemic change activities, by the entities in the areas of emphasis.

(3) Indicators of progress

(A) In general

In identifying progress made by the entities described in paragraph (1) in the areas of emphasis, the Secretary, in consultation with the Commissioner of the Administration on Developmental Disabilities and the entities, shall develop indicators for each area of emphasis.

(B) Proposed indicators
Not later than 180 days after October 30, 2000, the Secretary shall develop and publish in the Federal Register for public comment proposed indicators of progress for monitoring how entities described in paragraph (1) have addressed the areas of emphasis described in paragraph (2) in a manner that is responsive to the purpose of this subchapter and consistent with the policy described in section 15001 (c) of this title.

(C) Final indicators

Not later than October 1, 2001, the Secretary shall revise the proposed indicators of progress, to the extent necessary based on public comment, and publish final indicators of progress in the Federal Register.

(D) Specific measures

At a minimum, the indicators of progress shall be used to describe and measure—

(i) the satisfaction of individuals with developmental disabilities with the advocacy, capacity building, and systemic change activities provided under parts B, C, and D of this subchapter;

(ii) the extent to which the advocacy, capacity building, and systemic change activities provided through parts B, C, and D of this subchapter result in improvements in—

(I) the ability of individuals with developmental disabilities to make choices and exert control over the type, intensity, and timing of services, supports, and assistance that the individuals have used;

(II) the ability of individuals with developmental disabilities to participate in the full range of community life with persons of the individuals’ choice; and

(III) the ability of individuals with developmental disabilities to access services, supports, and assistance in a manner that ensures that such an individual is free from abuse, neglect, sexual and financial exploitation, violation of legal and human rights, and the inappropriate use of restraints and seclusion; and

(iii) the extent to which the entities described in paragraph (1) collaborate with each other to achieve the purpose of this subchapter and the policy described in section 15001 (c) of this title.

(4) Time line for compliance with indicators of progress

The Secretary shall require entities described in paragraph (1) to meet the indicators of progress described in paragraph (3). For fiscal year 2002 and each year thereafter, the Secretary shall apply the indicators in monitoring entities described in paragraph (1), with respect to activities conducted after October 1, 2001.

(b) Time line for regulations

Except as otherwise expressly provided in this subchapter, the Secretary, not later than 1 year after October 30, 2000, shall promulgate such regulations as may be required for the implementation of this subchapter.

(c) Interagency committee

(1) In general

The Secretary shall maintain the interagency committee authorized in section 6007 of this title as in effect on the day before October 30, 2000, except as otherwise provided in this subsection.

(2) Composition

The interagency committee shall be composed of representatives of—

(A) the Administration on Developmental Disabilities, the Administration on Children, Youth, and Families, the Administration on Aging, and the Health Resources and Services Administration, of the Department of Health and Human Services; and
§ 15005. Reports of the Secretary

At least once every 2 years, the Secretary, using information submitted in the reports and information required under parts B, C, D, and E of this subchapter, shall prepare and submit to the President, Congress, and the National Council on Disability, a report that describes the goals and outcomes of programs supported under parts B, C, D, and E of this subchapter. In preparing the report, the Secretary shall provide—

(1) meaningful examples of how the councils, protection and advocacy systems, centers, and entities funded under parts B, C, D, and E of this subchapter, respectively—

(A) have undertaken coordinated activities with each other;
(B) have enhanced the ability of individuals with developmental disabilities and their families to participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life;
(C) have brought about advocacy, capacity building, and systemic change activities (including policy reform), and other actions on behalf of individuals with developmental disabilities and their families, including individuals who are traditionally unserved or underserved, particularly individuals who are members of ethnic and racial minority groups and individuals from underserved geographic areas; and
(D) have brought about advocacy, capacity building, and systemic change activities that affect individuals with disabilities other than individuals with developmental disabilities;

(2) information on the extent to which programs authorized under this subchapter have addressed—

(A) protecting individuals with developmental disabilities from abuse, neglect, sexual and financial exploitation, and violations of legal and human rights, so that those individuals are at no greater risk of harm than other persons in the general population; and
(B) reports of deaths of and serious injuries to individuals with developmental disabilities; and

(3) a summary of any incidents of noncompliance of the programs authorized under this subchapter with the provisions of this subchapter, and corrections made or actions taken to obtain compliance.
§ 15006. State control of operations

Except as otherwise specifically provided, nothing in this subchapter shall be construed as conferring on any Federal officer or employee the right to exercise any supervision or control over the administration, personnel, maintenance, or operation of any programs, services, and supports for individuals with developmental disabilities with respect to which any funds have been or may be expended under this subchapter.

§ 15007. Employment of individuals with disabilities

As a condition of providing assistance under this subchapter, the Secretary shall require that each recipient of such assistance take affirmative action to employ and advance in employment qualified individuals with disabilities on the same terms and conditions required with respect to the employment of such individuals under the provisions of title V of the Rehabilitation Act of 1973 (29 U.S.C. 791 et seq.) and the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.), that govern employment.

§ 15008. Construction

Nothing in this subchapter shall be construed to preclude an entity funded under this subchapter from engaging in advocacy, capacity building, and systemic change activities for individuals with developmental disabilities that may also have a positive impact on individuals with other disabilities.

§ 15009. Rights of individuals with developmental disabilities

(a) In general

Congress makes the following findings respecting the rights of individuals with developmental disabilities:

(1) Individuals with developmental disabilities have a right to appropriate treatment, services, and habilitation for such disabilities, consistent with section 15001 (c) of this title.
(2) The treatment, services, and habitation for an individual with developmental disabilities should be designed to maximize the potential of the individual and should be provided in the setting that is least restrictive of the individual’s personal liberty.

(3) The Federal Government and the States both have an obligation to ensure that public funds are provided only to institutional programs, residential programs, and other community programs, including educational programs in which individuals with developmental disabilities participate, that—

(A) provide treatment, services, and habilitation that are appropriate to the needs of such individuals; and

(B) meet minimum standards relating to—

(i) provision of care that is free of abuse, neglect, sexual and financial exploitation, and violations of legal and human rights and that subjects individuals with developmental disabilities to no greater risk of harm than others in the general population;

(ii) provision to such individuals of appropriate and sufficient medical and dental services;

(iii) prohibition of the use of physical restraint and seclusion for such an individual unless absolutely necessary to ensure the immediate physical safety of the individual or others, and prohibition of the use of such restraint and seclusion as a punishment or as a substitute for a habilitation program;

(iv) prohibition of the excessive use of chemical restraints on such individuals and the use of such restraints as punishment or as a substitute for a habilitation program or in quantities that interfere with services, treatment, or habilitation for such individuals; and

(v) provision for close relatives or guardians of such individuals to visit the individuals without prior notice.

(4) All programs for individuals with developmental disabilities should meet standards—

(A) that are designed to assure the most favorable possible outcome for those served; and

(B) (i) in the case of residential programs serving individuals in need of comprehensive health-related, habilitative, assistive technology or rehabilitative services, that are at least equivalent to those standards applicable to intermediate care facilities for the mentally retarded, promulgated in regulations of the Secretary on June 3, 1988, as appropriate, taking into account the size of the institutions and the service delivery arrangements of the facilities of the programs;

(ii) in the case of other residential programs for individuals with developmental disabilities, that assure that—

(I) care is appropriate to the needs of the individuals being served by such programs;

(II) the individuals admitted to facilities of such programs are individuals whose needs can be met through services provided by such facilities; and

(III) the facilities of such programs provide for the humane care of the residents of the facilities, are sanitary, and protect their rights; and

(iii) in the case of nonresidential programs, that assure that the care provided by such programs is appropriate to the individuals served by the programs.

(b) Clarification

The rights of individuals with developmental disabilities described in findings made in this section shall be considered to be in addition to any constitutional or other rights otherwise afforded to all individuals.

Footnotes

1 So in original. Probably should be “habilitation”.

Part B—Federal Assistance to State Councils on Developmental Disabilities

§ 15021. Purpose

The purpose of this part is to provide for allotments to support State Councils on Developmental Disabilities (referred to individually in this part as a “Council”) in each State to—

1. engage in advocacy, capacity building, and systemic change activities that are consistent with the purpose described in section 15001 (b) of this title and the policy described in section 15001 (c) of this title; and

2. contribute to a coordinated, consumer- and family-centered, consumer- and family-directed, comprehensive system of community services, individualized supports, and other forms of assistance that enable individuals with developmental disabilities to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life.


§ 15022. State allotments

(a) Allotments

1. In general

(A) Authority

For each fiscal year, the Secretary shall, in accordance with regulations and this paragraph, allot the sums appropriated for such year under section 15029 of this title among the States on the basis of—

(i) the population;

(ii) the extent of need for services for individuals with developmental disabilities; and

(iii) the financial need,

of the respective States.

(B) Use of funds

Sums allotted to the States under this section shall be used to pay for the Federal share of the cost of carrying out projects in accordance with State plans approved under section 15024 of this title for the provision under such plans of services for individuals with developmental disabilities.

(2) Adjustments

The Secretary may make adjustments in the amounts of State allotments based on clauses (i), (ii), and (iii) of paragraph (1)(A) not more often than annually. The Secretary shall notify each State of any adjustment made under this paragraph and the percentage of the total sums appropriated under section 15029 of this title that the adjusted allotment represents not later than 6 months before the beginning of the fiscal year in which such adjustment is to take effect.

(3) Minimum allotment for appropriations less than or equal to $70,000,000

(A) In general

Except as provided in paragraph (4), for any fiscal year the allotment under this section—

(i) to each of American Samoa, Guam, the United States Virgin Islands, or the Commonwealth of the Northern Mariana Islands may not be less than $210,000; and

(ii) to any State not described in clause (i) may not be less than $400,000, the amount received by the State for the previous year, or the amount of Federal appropriations received in fiscal year 2000, 2001, or 2002, whichever is greater.
(B) Reduction of allotment

Notwithstanding subparagraph (A), if the aggregate of the amounts to be allotted to the States pursuant to subparagraph (A) for any fiscal year exceeds the total amount appropriated under section 15029 of this title for such fiscal year, the amount to be allotted to each State for such fiscal year shall be proportionately reduced.

(4) Minimum allotment for appropriations in excess of $70,000,000

(A) In general

In any case in which the total amount appropriated under section 15029 of this title for a fiscal year is more than $70,000,000, the allotment under this section for such fiscal year—

(i) to each of American Samoa, Guam, the United States Virgin Islands, or the Commonwealth of the Northern Mariana Islands may not be less than $220,000; and

(ii) to any State not described in clause (i) may not be less than $450,000, the amount received by the State for the previous year, or the amount of Federal appropriations received in fiscal year 2000, 2001, or 2002, whichever is greater.

(B) Reduction of allotment

The requirements of paragraph (3)(B) shall apply with respect to amounts to be allotted to States under subparagraph (A), in the same manner and to the same extent as such requirements apply with respect to amounts to be allotted to States under paragraph (3)(A).

(5) State supports, services, and other activities

In determining, for purposes of paragraph (1)(A)(ii), the extent of need in any State for services for individuals with developmental disabilities, the Secretary shall take into account the scope and extent of the services, supports, and assistance described, pursuant to section 15024(c)(3)(A) of this title, in the State plan of the State.

(6) Increase in allotments

In any year in which the total amount appropriated under section 15029 of this title for a fiscal year exceeds the total amount appropriated under such section (or a corresponding provision) for the preceding fiscal year by a percentage greater than the most recent percentage change in the Consumer Price Index published by the Secretary of Labor under section 720(c)(1) of title 29 (if the percentage change indicates an increase), the Secretary shall increase each of the minimum allotments described in paragraphs (3) and (4). The Secretary shall increase each minimum allotment by an amount that bears the same ratio to the amount of such minimum allotment (including any increases in such minimum allotment under this paragraph (or a corresponding provision) for prior fiscal years) as the amount that is equal to the difference between—

(A) the total amount appropriated under section 15029 of this title for the fiscal year for which the increase in the minimum allotment is being made; minus

(B) the total amount appropriated under section 15029 of this title (or a corresponding provision) for the immediately preceding fiscal year,

bears to the total amount appropriated under section 15029 of this title (or a corresponding provision) for such preceding fiscal year.

(b) Unobligated funds

Any amount paid to a State for a fiscal year and remaining unobligated at the end of such year shall remain available to such State for the next fiscal year for the purposes for which such amount was paid.

(c) Obligation of funds

For the purposes of this part, State Interagency Agreements are considered valid obligations for the purpose of obligating Federal funds allotted to the State under this part.

(d) Cooperative efforts between States
If a State plan approved in accordance with section 15024 of this title provides for cooperative or joint effort between or among States or agencies, public or private, in more than 1 State, portions of funds allotted to 1 or more States described in this subsection may be combined in accordance with the agreements between the States or agencies involved.

(e) Reallotments

(1) In general

If the Secretary determines that an amount of an allotment to a State for a period (of a fiscal year or longer) will not be required by the State during the period for the purpose for which the allotment was made, the Secretary may reallocate the amount.

(2) Timing

The Secretary may make such a reallocation from time to time, on such date as the Secretary may fix, but not earlier than 30 days after the Secretary has published notice of the intention of the Secretary to make the reallocation in the Federal Register.

(3) Amounts

The Secretary shall reallocate the amount to other States with respect to which the Secretary has not made that determination. The Secretary shall reallocate the amount in proportion to the original allotments of the other States for such fiscal year, but shall reduce such proportionate amount for any of the other States to the extent the proportionate amount exceeds the sum that the Secretary estimates the State needs and will be able to use during such period.

(4) Reallocation of reductions

The Secretary shall similarly reallocate the total of the reductions among the States whose proportionate amounts were not so reduced.

(5) Treatment

Any amount reallocated to a State under this subsection for a fiscal year shall be deemed to be a part of the allotment of the State under subsection (a) of this section for such fiscal year.


Amendments

2003—Subsec. (a)(3)(A)(ii), (4)(A)(ii). Pub. L. 108–154 inserted before period at end “, the amount received by the State for the previous year, or the amount of Federal appropriations received in fiscal year 2000, 2001, or 2002, whichever is greater”.

Effective Date of 2003 Amendment


§ 15023. Payments to the States for planning, administration, and services

(a) State plan expenditures

From each State’s allotments for a fiscal year under section 15022 of this title, the Secretary shall pay to the State the Federal share of the cost, other than the cost for construction, incurred during such year for activities carried out under the State plan approved under section 15024 of this title. The Secretary shall make such payments from time to time in advance on the basis of estimates by the Secretary of the sums the State will expend for the cost under the State plan. The Secretary shall make such adjustments as may be necessary to the payments on account of previously made underpayments or overpayments under this section.
(b) Designated State agency expenditures

The Secretary may make payments to a State for the portion described in section 15024 (c)(5)(B)(vi) of this title in advance or by way of reimbursement, and in such installments as the Secretary may determine.


§ 15024. State plan

(a) In general

Any State desiring to receive assistance under this part shall submit to the Secretary, and obtain approval of, a 5-year strategic State plan under this section.

(b) Planning cycle

The plan described in subsection (a) of this section shall be updated as appropriate during the 5-year period.

(c) State plan requirements

In order to be approved by the Secretary under this section, a State plan shall meet each of the following requirements:

(1) State Council

The plan shall provide for the establishment and maintenance of a Council in accordance with section 15025 of this title and describe the membership of such Council.

(2) Designated State agency

The plan shall identify the agency or office within the State designated to support the Council in accordance with this section and section 15025 (d) of this title (referred to in this part as a “designated State agency”).

(3) Comprehensive review and analysis

The plan shall describe the results of a comprehensive review and analysis of the extent to which services, supports, and other assistance are available to individuals with developmental disabilities and their families, and the extent of unmet needs for services, supports, and other assistance for those individuals and their families, in the State. The results of the comprehensive review and analysis shall include—

(A) a description of the services, supports, and other assistance being provided to individuals with developmental disabilities and their families under other federally assisted State programs, plans, and policies under which the State operates and in which individuals with developmental disabilities are or may be eligible to participate, including particularly programs relating to the areas of emphasis, including—

(i) medical assistance, maternal and child health care, services for children with special health care needs, children’s mental health services, comprehensive health and mental health services, and institutional care options;
(ii) job training, job placement, worksite accommodation, and vocational rehabilitation, and other work assistance programs; and
(iii) social, child welfare, aging, independent living, and rehabilitation and assistive technology services, and such other services as the Secretary may specify;

(B) a description of the extent to which agencies operating such other federally assisted State programs, including activities authorized under section 3003 or 3004 of title 29, pursue interagency initiatives to improve and enhance community services, individualized supports, and other forms of assistance for individuals with developmental disabilities;
(C) an analysis of the extent to which community services and opportunities related to the areas of emphasis directly benefit individuals with developmental disabilities, especially with regard to their ability to access and use services provided in their communities, to participate in opportunities, activities, and events offered in their communities, and to contribute to community life, identifying particularly—

(i) the degree of support for individuals with developmental disabilities that are attributable to either physical impairment, mental impairment, or a combination of physical and mental impairments;

(ii) criteria for eligibility for services, including specialized services and special adaptation of generic services provided by agencies within the State, that may exclude individuals with developmental disabilities from receiving services described in this clause;

(iii) the barriers that impede full participation of members of unserved and underserved groups of individuals with developmental disabilities and their families;

(iv) the availability of assistive technology, assistive technology services, or rehabilitation technology, or information about assistive technology, assistive technology services, or rehabilitation technology to individuals with developmental disabilities;

(v) the numbers of individuals with developmental disabilities on waiting lists for services described in this subparagraph;

(vi) a description of the adequacy of current resources and projected availability of future resources to fund services described in this subparagraph;

(vii) a description of the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities who are in facilities receive (based in part on each independent review (pursuant to section 1396a (a)(30)(C) of this title) of an Intermediate Care Facility (Mental Retardation) within the State, which the State shall provide to the Council not later than 30 days after the availability of the review); and

(viii) to the extent that information is available, a description of the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities who are served through home and community-based waivers (authorized under section 1396n (c) of this title) receive;

(D) a description of how entities funded under parts C and D of this subchapter, through interagency agreements or other mechanisms, collaborated with the entity funded under this part in the State, each other, and other entities to contribute to the achievement of the purpose of this part; and

(E) the rationale for the goals related to advocacy, capacity building, and systemic change to be undertaken by the Council to contribute to the achievement of the purpose of this part.

(4) Plan goals

The plan shall focus on Council efforts to bring about the purpose of this part, by—

(A) specifying 5-year goals, as developed through data driven strategic planning, for advocacy, capacity building, and systemic change related to the areas of emphasis, to be undertaken by the Council, that—

(i) are derived from the unmet needs of individuals with developmental disabilities and their families identified under paragraph (3); and

(ii) include a goal, for each year of the grant, to—

(I) establish or strengthen a program for the direct funding of a State self-advocacy organization led by individuals with developmental disabilities;
(II) support opportunities for individuals with developmental disabilities who are considered leaders to provide leadership training to individuals with developmental disabilities who may become leaders; and

(III) support and expand participation of individuals with developmental disabilities in cross-disability and culturally diverse leadership coalitions; and

(B) for each year of the grant, describing—

(i) the goals to be achieved through the grant, which, beginning in fiscal year 2002, shall be consistent with applicable indicators of progress described in section 15004 (a)(3) of this title;

(ii) the strategies to be used in achieving each goal; and

(iii) the method to be used to determine if each goal has been achieved.

(5) Assurances

(A) In general

The plan shall contain or be supported by assurances and information described in subparagraphs (B) through (N) that are satisfactory to the Secretary.

(B) Use of funds

With respect to the funds paid to the State under section 15022 of this title, the plan shall provide assurances that—

(i) not less than 70 percent of such funds will be expended for activities related to the goals described in paragraph (4);

(ii) such funds will contribute to the achievement of the purpose of this part in various political subdivisions of the State;

(iii) such funds will be used to supplement, and not supplant, the non-Federal funds that would otherwise be made available for the purposes for which the funds paid under section 15022 of this title are provided;

(iv) such funds will be used to complement and augment rather than duplicate or replace services for individuals with developmental disabilities and their families who are eligible for Federal assistance under other State programs;

(v) part of such funds will be made available by the State to public or private entities;

(vi) at the request of any State, a portion of such funds provided to such State under this part for any fiscal year shall be available to pay up to 1/2 (or the entire amount if the Council is the designated State agency) of the expenditures found to be necessary by the Secretary for the proper and efficient exercise of the functions of the designated State agency, except that not more than 5 percent of such funds provided to such State for any fiscal year, or $50,000, whichever is less, shall be made available for total expenditures for such purpose by the designated State agency; and

(vii) not more than 20 percent of such funds will be allocated to the designated State agency for service demonstrations by such agency that—

(I) contribute to the achievement of the purpose of this part; and

(II) are explicitly authorized by the Council.

(C) State financial participation

The plan shall provide assurances that there will be reasonable State financial participation in the cost of carrying out the plan.

(D) Conflict of interest

The plan shall provide an assurance that no member of such Council will cast a vote on any matter that would provide direct financial benefit to the member or otherwise give the appearance of a conflict of interest.
(E) Urban and rural poverty areas

The plan shall provide assurances that special financial and technical assistance will be given to organizations that provide community services, individualized supports, and other forms of assistance to individuals with developmental disabilities who live in areas designated as urban or rural poverty areas.

(F) Program accessibility standards

The plan shall provide assurances that programs, projects, and activities funded under the plan, and the buildings in which such programs, projects, and activities are operated, will meet standards prescribed by the Secretary in regulations and all applicable Federal and State accessibility standards, including accessibility requirements of the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.), section 794d of title 29, and the Fair Housing Act (42 U.S.C. 3601 et seq.).

(G) Individualized services

The plan shall provide assurances that any direct services provided to individuals with developmental disabilities and funded under the plan will be provided in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of such individual.

(H) Human rights

The plan shall provide assurances that the human rights of the individuals with developmental disabilities (especially individuals without familial protection) who are receiving services under programs assisted under this part will be protected consistent with section 15009 of this title (relating to rights of individuals with developmental disabilities).

(I) Minority participation

The plan shall provide assurances that the State has taken affirmative steps to assure that participation in programs funded under this part is geographically representative of the State, and reflects the diversity of the State with respect to race and ethnicity.

(J) Employee protections

The plan shall provide assurances that fair and equitable arrangements (as determined by the Secretary after consultation with the Secretary of Labor) will be provided to protect the interests of employees affected by actions taken under the plan to provide community living activities, including arrangements designed to preserve employee rights and benefits and provide training and retraining of such employees where necessary, and arrangements under which maximum efforts will be made to guarantee the employment of such employees.

(K) Staff assignments

The plan shall provide assurances that the staff and other personnel of the Council, while working for the Council, will be responsible solely for assisting the Council in carrying out the duties of the Council under this part and will not be assigned duties by the designated State agency, or any other agency, office, or entity of the State.

(L) Noninterference

The plan shall provide assurances that the designated State agency, and any other agency, office, or entity of the State, will not interfere with the advocacy, capacity building, and systemic change activities, budget, personnel, State plan development, or plan implementation of the Council, except that the designated State agency shall have the authority necessary to carry out the responsibilities described in section 15025 (d)(3) of this title.

(M) State quality assurance
The plan shall provide assurances that the Council will participate in the planning, design or redesign, and monitoring of State quality assurance systems that affect individuals with developmental disabilities.

(N) Other assurances

The plan shall contain such additional information and assurances as the Secretary may find necessary to carry out the provisions (including the purpose) of this part.

(d) Public input and review, submission, and approval

(1) Public input and review

The plan shall be based on public input. The Council shall make the plan available for public review and comment, after providing appropriate and sufficient notice in accessible formats of the opportunity for such review and comment. The Council shall revise the plan to take into account and respond to significant comments.

(2) Consultation with the designated State agency

Before the plan is submitted to the Secretary, the Council shall consult with the designated State agency to ensure that the State plan is consistent with State law and to obtain appropriate State plan assurances.

(3) Plan approval

The Secretary shall approve any State plan and, as appropriate, amendments of such plan that comply with the provisions of subsections (a), (b), and (c) of this section and this subsection. The Secretary may take final action to disapprove a State plan after providing reasonable notice and an opportunity for a hearing to the State.


References in Text


The Fair Housing Act, referred to in subsec. (c)(5)(F), is title VIII of Pub. L. 90–284, Apr. 11, 1968, 82 Stat. 81, as amended, which is classified principally to subchapter I (§ 3601 et seq.) of chapter 45 of this title. For complete classification of this Act to the Code, see Short Title note set out under section 3601 of this title and Tables.

Amendments

2004—Subsec. (c)(3)(B). Pub. L. 108–364 substituted “section 3003 or 3004 of title 29” for “section 3011 or 3012 of title 29”.

§ 15025. State Councils on Developmental Disabilities and designated State agencies

(a) In general

Each State that receives assistance under this part shall establish and maintain a Council to undertake advocacy, capacity building, and systemic change activities (consistent with subsections (b) and (c) of section 15001 of this title) that contribute to a coordinated, consumer- and family-centered, consumer- and family-directed, comprehensive system of community services, individualized supports, and other forms of assistance that contribute to the achievement of the purpose of this part. The Council shall have the authority to fulfill the responsibilities described in subsection (c) of this section.

(b) Council membership

(1) Council appointments
(A) In general

The members of the Council of a State shall be appointed by the Governor of the State from among the residents of that State.

(B) Recommendations

The Governor shall select members of the Council, at the discretion of the Governor, after soliciting recommendations from organizations representing a broad range of individuals with developmental disabilities and individuals interested in individuals with developmental disabilities, including the non-State agency members of the Council. The Council may, at the initiative of the Council, or on the request of the Governor, coordinate Council and public input to the Governor regarding all recommendations.

(C) Representation

The membership of the Council shall be geographically representative of the State and reflect the diversity of the State with respect to race and ethnicity.

(2) Membership rotation

The Governor shall make appropriate provisions to rotate the membership of the Council. Such provisions shall allow members to continue to serve on the Council until such members’ successors are appointed. The Council shall notify the Governor regarding membership requirements of the Council, and shall notify the Governor when vacancies on the Council remain unfilled for a significant period of time.

(3) Representation of individuals with developmental disabilities

Not less than 60 percent of the membership of each Council shall consist of individuals who are—

(A) (i) individuals with developmental disabilities;
    (ii) parents or guardians of children with developmental disabilities; or
    (iii) immediate relatives or guardians of adults with mentally impairing developmental disabilities who cannot advocate for themselves; and

(B) not employees of a State agency that receives funds or provides services under this part, and who are not managing employees (as defined in section 1126(b) of the Social Security Act (42 U.S.C. 1320a–5 (b)) of any other entity that receives funds or provides services under this part.

(4) Representation of agencies and organizations

(A) In general

Each Council shall include—

(i) representatives of relevant State entities, including—
    (II) Centers in the State; and
    (III) the State protection and advocacy system; and

(ii) representatives, at all times, of local and nongovernmental agencies, and private nonprofit groups concerned with services for individuals with developmental disabilities in the State in which such agencies and groups are located.

(B) Authority and limitations

The representatives described in subparagraph (A) shall—
(i) have sufficient authority to engage in policy planning and implementation on behalf of the department, agency, or program such representatives represent; and

(ii) recuse themselves from any discussion of grants or contracts for which such representatives’ departments, agencies, or programs are grantees, contractors, or applicants and comply with the conflict of interest assurance requirement under section 15024(c)(5)(D) of this title.

(5) Composition of membership with developmental disabilities

Of the members of the Council described in paragraph (3)—

(A) 1/3 shall be individuals with developmental disabilities described in paragraph (3)(A)(i);

(B) 1/3 shall be parents or guardians of children with developmental disabilities described in paragraph (3)(A)(ii), or immediate relatives or guardians of adults with developmental disabilities described in paragraph (3)(A)(iii); and

(C) 1/3 shall be a combination of individuals described in paragraph (3)(A).

(6) Institutionalized individuals

(A) In general

Of the members of the Council described in paragraph (5), at least 1 shall be an immediate relative or guardian of an individual with a developmental disability who resides or previously resided in an institution or shall be an individual with a developmental disability who resides or previously resided in an institution.

(B) Limitation

Subparagraph (A) shall not apply with respect to a State if such an individual does not reside in that State.

(c) Council responsibilities

(1) In general

A Council, through Council members, staff, consultants, contractors, or subgrantees, shall have the responsibilities described in paragraphs (2) through (10).

(2) Advocacy, capacity building, and systemic change activities

The Council shall serve as an advocate for individuals with developmental disabilities and conduct or support programs, projects, and activities that carry out the purpose of this part.

(3) Examination of goals

At the end of each grant year, each Council shall—

(A) determine the extent to which each goal of the Council was achieved for that year;

(B) determine to the extent that each goal was not achieved, the factors that impeded the achievement;

(C) determine needs that require amendment of the 5-year strategic State plan required under section 15024 of this title;

(D) separately determine the information on the self-advocacy goal described in section 15024(c)(4)(A)(ii) of this title; and

(E) determine customer satisfaction with Council supported or conducted activities.

(4) State plan development

The Council shall develop the State plan and submit the State plan to the Secretary after consultation with the designated State agency under the State plan. Such consultation shall be solely for the purposes of obtaining State assurances and ensuring consistency of the plan with State law.

(5) State plan implementation
(A) In general

The Council shall implement the State plan by conducting and supporting advocacy, capacity building, and systemic change activities such as those described in subparagraphs (B) through (L).

(B) Outreach

The Council may support and conduct outreach activities to identify individuals with developmental disabilities and their families who otherwise might not come to the attention of the Council and assist and enable the individuals and families to obtain services, individualized supports, and other forms of assistance, including access to special adaptation of generic community services or specialized services.

(C) Training

The Council may support and conduct training for persons who are individuals with developmental disabilities, their families, and personnel (including professionals, paraprofessionals, students, volunteers, and other community members) to enable such persons to obtain access to, or to provide, community services, individualized supports, and other forms of assistance, including special adaptation of generic community services or specialized services for individuals with developmental disabilities and their families. To the extent that the Council supports or conducts training activities under this subparagraph, such activities shall contribute to the achievement of the purpose of this part.

(D) Technical assistance

The Council may support and conduct technical assistance activities to assist public and private entities to contribute to the achievement of the purpose of this part.

(E) Supporting and educating communities

The Council may support and conduct activities to assist neighborhoods and communities to respond positively to individuals with developmental disabilities and their families—

(i) by encouraging local networks to provide informal and formal supports;

(ii) through education; and

(iii) by enabling neighborhoods and communities to offer such individuals and their families access to and use of services, resources, and opportunities.

(F) Interagency collaboration and coordination

The Council may support and conduct activities to promote interagency collaboration and coordination to better serve, support, assist, or advocate for individuals with developmental disabilities and their families.

(G) Coordination with related councils, committees, and programs

The Council may support and conduct activities to enhance coordination of services with—

(i) other councils, entities, or committees, authorized by Federal or State law, concerning individuals with disabilities (such as the State interagency coordinating council established under part C of the Individuals with Disabilities Education Act (20 U.S.C. 1431 et seq.), the State Rehabilitation Council and the Statewide Independent Living Council established under the Rehabilitation Act of 1973 (29 U.S.C. 701 et seq.), the State mental health planning council established under subtitle B of title XIX of the Public Health Service Act [42 U.S.C. 300x et seq.], and the activities authorized under section 3003 or 3004 of title 29, and entities carrying out other similar councils, entities, or committees);
(ii) parent training and information centers under part D of the Individuals with Disabilities Education Act (20 U.S.C. 1451 et seq.) and other entities carrying out federally funded projects that assist parents of children with disabilities; and

(iii) other groups interested in advocacy, capacity building, and systemic change activities to benefit individuals with disabilities.

(H) Barrier elimination, systems design and redesign

The Council may support and conduct activities to eliminate barriers to access and use of community services by individuals with developmental disabilities, enhance systems design and redesign, and enhance citizen participation to address issues identified in the State plan.

(I) Coalition development and citizen participation

The Council may support and conduct activities to educate the public about the capabilities, preferences, and needs of individuals with developmental disabilities and their families and to develop and support coalitions that support the policy agenda of the Council, including training in self-advocacy, education of policymakers, and citizen leadership skills.

(J) Informing policymakers

The Council may support and conduct activities to provide information to policymakers by supporting and conducting studies and analyses, gathering information, and developing and disseminating model policies and procedures, information, approaches, strategies, findings, conclusions, and recommendations. The Council may provide the information directly to Federal, State, and local policymakers, including Congress, the Federal executive branch, the Governors, State legislatures, and State agencies, in order to increase the ability of such policymakers to offer opportunities and to enhance or adapt generic services to meet the needs of, or provide specialized services to, individuals with developmental disabilities and their families.

(K) Demonstration of new approaches to services and supports

(i) In general

The Council may support and conduct, on a time-limited basis, activities to demonstrate new approaches to serving individuals with developmental disabilities that are a part of an overall strategy for systemic change. The strategy may involve the education of policymakers and the public about how to deliver effectively, to individuals with developmental disabilities and their families, services, supports, and assistance that contribute to the achievement of the purpose of this part.

(ii) Sources of funding

The Council may carry out this subparagraph by supporting and conducting demonstration activities through sources of funding other than funding provided under this part, and by assisting entities conducting demonstration activities to develop strategies for securing funding from other sources.

(L) Other activities

The Council may support and conduct other advocacy, capacity building, and systemic change activities to promote the development of a coordinated, consumer- and family-centered, consumer- and family-directed, comprehensive system of community services, individualized supports, and other forms of assistance that contribute to the achievement of the purpose of this part.

(6) Review of designated State agency

The Council shall periodically review the designated State agency and activities carried out under this part by the designated State agency and make any recommendations for change to the Governor.
(7) Reports

Beginning in fiscal year 2002, the Council shall annually prepare and transmit to the Secretary a report. Each report shall be in a form prescribed by the Secretary by regulation under section 15004(b) of this title. Each report shall contain information about the progress made by the Council in achieving the goals of the Council (as specified in section 15024(c)(4) of this title), including—

(A) a description of the extent to which the goals were achieved;
(B) a description of the strategies that contributed to achieving the goals;
(C) to the extent to which the goals were not achieved, a description of factors that impeded the achievement;
(D) separate information on the self-advocacy goal described in section 15024(c)(4)(A)(ii) of this title;
(E) (i) as appropriate, an update on the results of the comprehensive review and analysis described in section 15024(c)(3) of this title; and
(ii) information on consumer satisfaction with Council supported or conducted activities;
(F) (i) a description of the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities in Intermediate Care Facilities (Mental Retardation) receive; and
(ii) a description of the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities served through home and community-based waivers (authorized under section 1915(c) of the Social Security Act (42 U.S.C. 1396n (c)) receive;
(G) an accounting of the manner in which funds paid to the State under this part for a fiscal year were expended;
(H) a description of—
(i) resources made available to carry out activities to assist individuals with developmental disabilities that are directly attributable to Council actions; and
(ii) resources made available for such activities that are undertaken by the Council in collaboration with other entities; and
(I) a description of the method by which the Council will widely disseminate the annual report to affected constituencies and the general public and will assure that the report is available in accessible formats.

(8) Budget

Each Council shall prepare, approve, and implement a budget using amounts paid to the State under this part to fund and implement all programs, projects, and activities carried out under this part, including—

(A) (i) conducting such hearings and forums as the Council may determine to be necessary to carry out the duties of the Council; and
(ii) as determined in Council policy—
(I) reimbursing members of the Council for reasonable and necessary expenses (including expenses for child care and personal assistance services) for attending Council meetings and performing Council duties;
(II) paying a stipend to a member of the Council, if such member is not employed or must forfeit wages from other employment, to attend Council meetings and perform other Council duties;
(III) supporting Council member and staff travel to authorized training and technical assistance activities including in-service training and leadership development activities; and

(IV) carrying out appropriate subcontracting activities;

(B) hiring and maintaining such numbers and types of staff (qualified by training and experience) and obtaining the services of such professional, consulting, technical, and clerical staff (qualified by training and experience), consistent with State law, as the Council determines to be necessary to carry out the functions of the Council under this part, except that such State shall not apply hiring freezes, reductions in force, prohibitions on travel, or other policies to the staff of the Council, to the extent that such policies would impact the staff or functions funded with Federal funds, or would prevent the Council from carrying out the functions of the Council under this part; and

(C) directing the expenditure of funds for grants, contracts, interagency agreements that are binding contracts, and other activities authorized by the State plan approved under section 15024 of this title.

(9) Staff hiring and supervision

The Council shall, consistent with State law, recruit and hire a Director of the Council, should the position of Director become vacant, and supervise and annually evaluate the Director. The Director shall hire, supervise, and annually evaluate the staff of the Council. Council recruitment, hiring, and dismissal of staff shall be conducted in a manner consistent with Federal and State nondiscrimination laws. Dismissal of personnel shall be conducted in a manner consistent with State law and personnel policies.

(10) Staff assignments

The staff of the Council, while working for the Council, shall be responsible solely for assisting the Council in carrying out the duties of the Council under this part and shall not be assigned duties by the designated State agency or any other agency or entity of the State.

(11) Construction

Nothing in this subchapter shall be construed to authorize a Council to direct, control, or exercise any policymaking authority or administrative authority over any program assisted under the Rehabilitation Act of 1973 (29 U.S.C. 701 et seq.) or the Individuals with Disabilities Education Act (20 U.S.C. 1400 et seq.).

(d) Designated State agency

(1) In general

Each State that receives assistance under this part shall designate a State agency that shall, on behalf of the State, provide support to the Council. After April 6, 1994, any designation of a State agency under this paragraph shall be made in accordance with the requirements of this subsection.

(2) Designation

(A) Type of agency

Except as provided in this subsection, the designated State agency shall be—

(i) the Council if such Council may be the designated State agency under the laws of the State;

(ii) a State agency that does not provide or pay for services for individuals with developmental disabilities; or

(iii) a State office, including the immediate office of the Governor of the State or a State planning office.

(B) Conditions for continuation of State service agency designation

(i) Designation before April 6, 1994
If a State agency that provides or pays for services for individuals with developmental disabilities was a designated State agency for purposes of part B of the Developmental Disabilities Assistance and Bill of Rights Act on April 6, 1994, and the Governor of the State (or the legislature, where appropriate and in accordance with State law) determines prior to June 30, 1994, not to change the designation of such agency, such agency may continue to be a designated State agency for purposes of this part.

(ii) Criteria for continued designation

The determination, at the discretion of the Governor (or the legislature, as the case may be), shall be made after—

(I) the Governor has considered the comments and recommendations of the general public and a majority of the non-State agency members of the Council with respect to the designation of such State agency; and

(II) the Governor (or the legislature, as the case may be) has made an independent assessment that the designation of such agency will not interfere with the budget, personnel, priorities, or other action of the Council, and the ability of the Council to serve as an independent advocate for individuals with developmental disabilities.

(C) Review of designation

The Council may request a review of and change in the designation of the designated State agency by the Governor (or the legislature, as the case may be). The Council shall provide documentation concerning the reason the Council desires a change to be made and make a recommendation to the Governor (or the legislature, as the case may be) regarding a preferred designated State agency.

(D) Appeal of designation

After the review is completed under subparagraph (C), a majority of the non-State agency members of the Council may appeal to the Secretary for a review of and change in the designation of the designated State agency if the ability of the Council to serve as an independent advocate is not assured because of the actions or inactions of the designated State agency.

(3) Responsibilities

(A) In general

The designated State agency shall, on behalf of the State, have the responsibilities described in subparagraphs (B) through (G).

(B) Support services

The designated State agency shall provide required assurances and support services as requested by and negotiated with the Council.

(C) Fiscal responsibilities

The designated State agency shall—

(i) receive, account for, and disburse funds under this part based on the State plan required in section 15024 of this title; and

(ii) provide for such fiscal control and fund accounting procedures as may be necessary to assure the proper disbursement of, and accounting for, funds paid to the State under this part.

(D) Records, access, and financial reports

The designated State agency shall keep and provide access to such records as the Secretary and the Council may determine to be necessary. The designated State agency, if other than the Council, shall provide timely financial reports at the request of the Council regarding the
status of expenditures, obligations, and liquidation by the agency or the Council, and the use of the Federal and non-Federal shares described in section 15026 of this title, by the agency or the Council.

(E) Non-Federal share
The designated State agency, if other than the Council, shall provide the required non-Federal share described in section 15026 (c) of this title.

(F) Assurances
The designated State agency shall assist the Council in obtaining the appropriate State plan assurances and in ensuring that the plan is consistent with State law.

(G) Memorandum of understanding
On the request of the Council, the designated State agency shall enter into a memorandum of understanding with the Council delineating the roles and responsibilities of the designated State agency.

(4) Use of funds for designated State agency responsibilities

(A) Condition for Federal funding

(i) In general
The Secretary shall provide amounts to a State under section 15024 (c)(5)(B)(vi) of this title for a fiscal year only if the State expends an amount from State sources for carrying out the responsibilities of the designated State agency under paragraph (3) for the fiscal year that is not less than the total amount the State expended from such sources for carrying out similar responsibilities for the previous fiscal year.

(ii) Exception
Clause (i) shall not apply in a year in which the Council is the designated State agency.

(B) Support services provided by other agencies
With the agreement of the designated State agency, the Council may use or contract with agencies other than the designated State agency to perform the functions of the designated State agency.

Footnotes
1 See References in Text note below.


References in Text

The Individuals with Disabilities Education Act, referred to in subsecs. (b)(4)(A)(i)(I) and (c)(5)(G)(i), (ii), (11), is title VI of Pub. L. 91–230, Apr. 13, 1970, 84 Stat. 175, as amended, which is classified generally to chapter 33 (§ 1400 et seq.) of Title 20, Education. Part C of the Act is classified generally to subchapter III (§ 1431 et seq.) of chapter 33 of Title 20. Part D of the Act is classified generally to subchapter IV (§ 1450 et seq.) of chapter 33 of Title 20. For complete classification of this Act to the Code, see section 1400 of Title 20 and Tables.


respective, of chapter 7 of this title. For complete classification of this Act to the Code, see section 1305 of this title and Tables.

The Public Health Service Act, referred to in subsec. (c)(5)(G)(i), is act July 1, 1944, ch. 373, 58 Stat. 682, as amended. The reference to subtitle B of title XIX of the Act probably means part B of title XIX of the Act which is classified generally to part B (§ 300x et seq.) of subchapter XVII of chapter 6A of this title. For complete classification of this Act to the Code, see Short Title note set out under section 201 of this title and Tables.


Amendments


Pub. L. 108–364 substituted “section 3003 or 3004 of title 29” for “section 3011 or 3012 of title 29”.

§ 15026. Federal and non-Federal share

(a) Aggregate cost

(1) In general

Except as provided in paragraphs (2) and (3), the Federal share of the cost of all projects in a State supported by an allotment to the State under this part may not be more than 75 percent of the aggregate necessary cost of such projects, as determined by the Secretary.

(2) Urban or rural poverty areas

In the case of projects whose activities or products target individuals with developmental disabilities who live in urban or rural poverty areas, as determined by the Secretary, the Federal share of the cost of all such projects may not be more than 90 percent of the aggregate necessary cost of such projects, as determined by the Secretary.

(3) State plan activities

In the case of projects undertaken by the Council or Council staff to implement State plan activities, the Federal share of the cost of all such projects may not be more than 100 percent of the aggregate necessary cost of such activities.

(b) Nonduplication

In determining the amount of any State’s Federal share of the cost of such projects incurred by such State under a State plan approved under section 15024 of this title, the Secretary shall not consider—

(1) any portion of such cost that is financed by Federal funds provided under any provision of law other than section 15022 of this title; and

(2) the amount of any non-Federal funds required to be expended as a condition of receipt of the Federal funds described in paragraph (1).

(c) Non-Federal share

(1) In-kind contributions

The non-Federal share of the cost of any project supported by an allotment under this part may be provided in cash or in kind, fairly evaluated, including plant, equipment, or services.

(2) Contributions of political subdivisions and public or private entities

(A) In general

Contributions to projects by a political subdivision of a State or by a public or private entity under an agreement with the State shall, subject to such limitations and conditions as the Secretary may by regulation prescribe under section 15004 (b) of this title, be considered to be contributions by such State, in the case of a project supported under this part.
(B) State contributions

State contributions, including contributions by the designated State agency to provide support services to the Council pursuant to section 15025 (d)(4) of this title, may be counted as part of such State’s non-Federal share of the cost of projects supported under this part.

(3) Variations of the non-Federal share

The non-Federal share required of each recipient of a grant from a Council under this part may vary.


§ 15027. Withholding of payments for planning, administration, and services

Whenever the Secretary, after providing reasonable notice and an opportunity for a hearing to the Council and the designated State agency, finds that—

(1) the Council or agency has failed to comply substantially with any of the provisions required by section 15024 of this title to be included in the State plan, particularly provisions required by paragraphs (4)(A) and (5)(B)(vii) of section 15024 (c) of this title, or with any of the provisions required by section 15025 (b)(3) of this title; or

(2) the Council or agency has failed to comply substantially with any regulations of the Secretary that are applicable to this part,

the Secretary shall notify such Council and agency that the Secretary will not make further payments to the State under section 15022 of this title (or, in the discretion of the Secretary, that further payments to the State under section 15022 of this title for activities for which there is such failure), until the Secretary is satisfied that there will no longer be such failure. Until the Secretary is so satisfied, the Secretary shall make no further payments to the State under section 15022 of this title, or shall limit further payments under section 15022 of this title to such State to activities for which there is no such failure.


§ 15028. Appeals by States

(a) Appeal

If any State is dissatisfied with the Secretary’s action under section 15024 (d)(3) or 15027 of this title, such State may appeal to the United States court of appeals for the circuit in which such State is located, by filing a petition with such court not later than 60 days after such action.

(b) Filing

The clerk of the court shall transmit promptly a copy of the petition to the Secretary, or any officer designated by the Secretary for that purpose. The Secretary shall file promptly with the court the record of the proceedings on which the Secretary based the action, as provided in section 2112 of title 28.

(c) Jurisdiction

Upon the filing of the petition, the court shall have jurisdiction to affirm the action of the Secretary or to set the action aside, in whole or in part, temporarily or permanently. Until the filing of the record, the Secretary may modify or set aside the order of the Secretary relating to the action.

(d) Findings and remand

The findings of the Secretary about the facts, if supported by substantial evidence, shall be conclusive, but the court, for good cause shown, may remand the case involved to the Secretary for further proceedings to take further evidence. On remand, the Secretary may make new or modified findings of fact and may modify the previous action of the Secretary, and shall file with the court the record of the
further proceedings. Such new or modified findings of fact shall likewise be conclusive if supported by substantial evidence.

(e) Finality

The judgment of the court affirming or setting aside, in whole or in part, any action of the Secretary shall be final, subject to review by the Supreme Court of the United States upon certiorari or certification as provided in section 1254 of title 28.

(f) Effect

The commencement of proceedings under this section shall not, unless so specifically ordered by a court, operate as a stay of the Secretary’s action.


§ 15029. Authorization of appropriations

(a) Funding for State allotments

Except as described in subsection (b) of this section, there are authorized to be appropriated for allotments under section 15022 of this title $76,000,000 for fiscal year 2001 and such sums as may be necessary for each of fiscal years 2002 through 2007.

(b) Reservation for technical assistance

(1) Lower appropriation years

For any fiscal year for which the amount appropriated under subsection (a) of this section is less than $76,000,000, the Secretary shall reserve funds in accordance with section 15083 (c) of this title to provide technical assistance to entities funded under this part.

(2) Higher appropriation years

For any fiscal year for which the amount appropriated under subsection (a) of this section is not less than $76,000,000, the Secretary shall reserve not less than $300,000 and not more than 1 percent of the amount appropriated under subsection (a) of this section to provide technical assistance to entities funded under this part.

Part C—Protection and Advocacy of Individual Rights

§ 15041. Purpose

The purpose of this part is to provide for allotments to support a protection and advocacy system (referred to in this part as a “system”) in each State to protect the legal and human rights of individuals with developmental disabilities in accordance with this part.


§ 15042. Allotments and payments

(a) Allotments

(1) In general

To assist States in meeting the requirements of section 15043 (a) of this title, the Secretary shall allot to the States the amounts appropriated under section 15045 of this title and not reserved under paragraph (6). Allotments and reallotments of such sums shall be made on the same basis as the allotments and reallotments are made under subsections (a)(1)(A) and (e) of section 15022 of this title, except as provided in paragraph (2).

(2) Minimum allotments

In any case in which—

(A) the total amount appropriated under section 15045 of this title for a fiscal year is not less than $20,000,000, the allotment under paragraph (1) for such fiscal year—

(i) to each of American Samoa, Guam, the United States Virgin Islands, and the Commonwealth of the Northern Mariana Islands may not be less than $107,000; and

(ii) to any State not described in clause (i) may not be less than $200,000; or

(B) the total amount appropriated under section 15045 of this title for a fiscal year is less than $20,000,000, the allotment under paragraph (1) for such fiscal year—

(i) to each of American Samoa, Guam, the United States Virgin Islands, and the Commonwealth of the Northern Mariana Islands may not be less than $80,000; and

(ii) to any State not described in clause (i) may not be less than $150,000.

(3) Reduction of allotment

Notwithstanding paragraphs (1) and (2), if the aggregate of the amounts to be allotted to the States pursuant to such paragraphs for any fiscal year exceeds the total amount appropriated for such allotments under section 15045 of this title for such fiscal year, the amount to be allotted to each State for such fiscal year shall be proportionately reduced.

(4) Increase in allotments

In any year in which the total amount appropriated under section 15045 of this title for a fiscal year exceeds the total amount appropriated under such section (or a corresponding provision) for the preceding fiscal year by a percentage greater than the most recent percentage change in the Consumer Price Index published by the Secretary of Labor under section 720 (c)(1) of title 29 (if the percentage change indicates an increase), the Secretary shall increase each of the minimum allotments described in subparagraphs (A) and (B) of paragraph (2). The Secretary shall increase each minimum allotment by an amount that bears the same ratio to the amount of such minimum allotment (including any increases in such minimum allotment under this paragraph (or a corresponding provision) for prior fiscal years) as the amount that is equal to the difference between—
(A) the total amount appropriated under section 15045 of this title for the fiscal year for which
the increase in the minimum allotment is being made; minus

(B) the total amount appropriated under section 15045 of this title (or a corresponding
provision) for the immediately preceding fiscal year,

bears to the total amount appropriated under section 15045 of this title (or a corresponding
provision) for such preceding fiscal year.

(5) Monitoring the administration of the system

In a State in which the system is housed in a State agency, the State may use not more than 5
percent of any allotment under this subsection for the costs of monitoring the administration of the
system required under section 15043 (a) of this title.

(6) Technical assistance and American Indian consortium

In any case in which the total amount appropriated under section 15045 of this title for a fiscal
year is more than $24,500,000, the Secretary shall—

(A) use not more than 2 percent of the amount appropriated to provide technical assistance to
eligible systems with respect to activities carried out under this part (consistent with requests
by such systems for such assistance for the year); and

(B) provide a grant in accordance with section 15043 (b) of this title, and in an amount
described in paragraph (2)(A)(i), to an American Indian consortium to provide protection and
advocacy services.

(b) Payment to systems

Notwithstanding any other provision of law, the Secretary shall pay directly to any system in a State
that complies with the provisions of this part the amount of the allotment made for the State under this
section, unless the system specifies otherwise.

(c) Unobligated funds

Any amount paid to a system under this part for a fiscal year and remaining unobligated at the end
of such year shall remain available to such system for the next fiscal year, for the purposes for which
such amount was paid.


§ 15043. System required

(a) System required

In order for a State to receive an allotment under part B of this subchapter or this part—

(1) the State shall have in effect a system to protect and advocate the rights of individuals with
developmental disabilities;

(2) such system shall—

(A) have the authority to—

(i) pursue legal, administrative, and other appropriate remedies or approaches to ensure
the protection of, and advocacy for, the rights of such individuals within the State who are
or who may be eligible for treatment, services, or habilitation, or who are being considered
for a change in living arrangements, with particular attention to members of ethnic and
racial minority groups; and

(ii) provide information on and referral to programs and services addressing the needs
of individuals with developmental disabilities;
(B) have the authority to investigate incidents of abuse and neglect of individuals with developmental disabilities if the incidents are reported to the system or if there is probable cause to believe that the incidents occurred;

(C) on an annual basis, develop, submit to the Secretary, and take action with regard to goals (each of which is related to 1 or more areas of emphasis) and priorities, developed through data driven strategic planning, for the system’s activities;

(D) on an annual basis, provide to the public, including individuals with developmental disabilities attributable to either physical impairment, mental impairment, or a combination of physical and mental impairment, and their representatives, and as appropriate, non-State agency representatives of the State Councils on Developmental Disabilities, and Centers, in the State, an opportunity to comment on—

(i) the goals and priorities established by the system and the rationale for the establishment of such goals; and

(ii) the activities of the system, including the coordination of services with the entities carrying out advocacy programs under the Rehabilitation Act of 1973 (29 U.S.C. 701 et seq.), the Older Americans Act of 1965 (42 U.S.C. 3001 et seq.), and the Protection and Advocacy for Mentally Ill Individuals Act of 1986 (42 U.S.C. 10801 et seq.), and with entities carrying out other related programs, including the parent training and information centers funded under the Individuals with Disabilities Education Act (20 U.S.C. 1400 et seq.), and activities authorized under section 3003 or 3004 of title 29;

(E) establish a grievance procedure for clients or prospective clients of the system to ensure that individuals with developmental disabilities have full access to services of the system;

(F) not be administered by the State Council on Developmental Disabilities;

(G) be independent of any agency that provides treatment, services, or habilitation to individuals with developmental disabilities;

(H) have access at reasonable times to any individual with a developmental disability in a location in which services, supports, and other assistance are provided to such an individual, in order to carry out the purpose of this part;

(I) have access to all records of—

(i) any individual with a developmental disability who is a client of the system if such individual, or the legal guardian, conservator, or other legal representative of such individual, has authorized the system to have such access;

(ii) any individual with a developmental disability, in a situation in which—

(I) the individual, by reason of such individual’s mental or physical condition, is unable to authorize the system to have such access;

(II) the individual does not have a legal guardian, conservator, or other legal representative, or the legal guardian of the individual is the State; and

(III) a complaint has been received by the system about the individual with regard to the status or treatment of the individual or, as a result of monitoring or other activities, there is probable cause to believe that such individual has been subject to abuse or neglect; and

(iii) any individual with a developmental disability, in a situation in which—

(I) the individual has a legal guardian, conservator, or other legal representative;

(II) a complaint has been received by the system about the individual with regard to the status or treatment of the individual or, as a result of monitoring or other activities, there is probable cause to believe that such individual has been subject to abuse or neglect;
(III) such representative has been contacted by such system, upon receipt of the name and address of such representative;

(IV) such system has offered assistance to such representative to resolve the situation; and

(V) such representative has failed or refused to act on behalf of the individual;

(J) (i) have access to the records of individuals described in subparagraphs (B) and (I), and other records that are relevant to conducting an investigation, under the circumstances described in those subparagraphs, not later than 3 business days after the system makes a written request for the records involved; and

(ii) have immediate access, not later than 24 hours after the system makes such a request, to the records without consent from another party, in a situation in which services, supports, and other assistance are provided to an individual with a developmental disability—

(I) if the system determines there is probable cause to believe that the health or safety of the individual is in serious and immediate jeopardy; or

(II) in any case of death of an individual with a developmental disability;

(K) hire and maintain sufficient numbers and types of staff (qualified by training and experience) to carry out such system’s functions, except that the State involved shall not apply hiring freezes, reductions in force, prohibitions on travel, or other policies to the staff of the system, to the extent that such policies would impact the staff or functions of the system funded with Federal funds or would prevent the system from carrying out the functions of the system under this part;

(L) have the authority to educate policymakers; and

(M) provide assurances to the Secretary that funds allotted to the State under section 15042 of this title will be used to supplement, and not supplant, the non-Federal funds that would otherwise be made available for the purposes for which the allotted funds are provided;

(3) to the extent that information is available, the State shall provide to the system—

(A) a copy of each independent review, pursuant to section 1396a (a)(30)(C) of this title, of an Intermediate Care Facility (Mental Retardation) within the State, not later than 30 days after the availability of such a review; and

(B) information about the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities who are served through home and community-based waivers (authorized under section 1396n (c) of this title) receive; and

(4) the agency implementing the system shall not be redesignated unless—

(A) there is good cause for the redesignation;

(B) the State has given the agency notice of the intention to make such redesignation, including notice regarding the good cause for such redesignation, and given the agency an opportunity to respond to the assertion that good cause has been shown;

(C) the State has given timely notice and an opportunity for public comment in an accessible format to individuals with developmental disabilities or their representatives; and

(D) the system has an opportunity to appeal the redesignation to the Secretary, on the basis that the redesignation was not for good cause.

(b) American Indian consortium

Upon application to the Secretary, an American Indian consortium established to provide protection and advocacy services under this part, shall receive funding pursuant to section 15042 (a)(6) of this title to provide the services. Such consortium shall be considered to be a system for purposes of this part and shall coordinate the services with other systems serving the same geographic area. The tribal
council that designates the consortium shall carry out the responsibilities and exercise the authorities specified for a State in this part, with regard to the consortium.

(c) Record

In this section, the term “record” includes—

(1) a report prepared or received by any staff at any location at which services, supports, or other assistance is provided to individuals with developmental disabilities;

(2) a report prepared by an agency or staff person charged with investigating reports of incidents of abuse or neglect, injury, or death occurring at such location, that describes such incidents and the steps taken to investigate such incidents; and

(3) a discharge planning record.

Footnotes

1 See References in Text note below.


References in Text


The Individuals with Disabilities Education Act, referred to in subsec. (a)(2)(D)(ii), is title VI of Pub. L. 91–230, Apr. 13, 1970, 84 Stat. 175, as amended, which is classified generally to chapter 33 (§ 1400 et seq.) of Title 20, Education. For complete classification of this Act to the Code, see section 1400 of Title 20 and Tables.

Amendments


§ 15044. Administration

(a) Governing board

In a State in which the system described in section 15043 of this title is organized as a private nonprofit entity with a multimember governing board, or a public system with a multimember governing board, such governing board shall be selected according to the policies and procedures of the system, except that—

(1) (A) the governing board shall be composed of members who broadly represent or are knowledgeable about the needs of the individuals served by the system;

(B) a majority of the members of the board shall be—

(i) individuals with disabilities, including individuals with developmental disabilities, who are eligible for services, or have received or are receiving services through the system; or
(ii) parents, family members, guardians, advocates, or authorized representatives of individuals referred to in clause (i); and

(C) the board may include a representative of the State Council on Developmental Disabilities, the Centers in the State, and the self-advocacy organization described in section 15024 (c)(4)(A)(ii)(I) of this title;

(2) not more than 1/3 of the members of the governing board may be appointed by the chief executive officer of the State involved, in the case of any State in which such officer has the authority to appoint members of the board;

(3) the membership of the governing board shall be subject to term limits set by the system to ensure rotating membership;

(4) any vacancy in the board shall be filled not later than 60 days after the date on which the vacancy occurs; and

(5) in a State in which the system is organized as a public system without a multimember governing or advisory board, the system shall establish an advisory council—

(A) that shall advise the system on policies and priorities to be carried out in protecting and advocating the rights of individuals with developmental disabilities; and

(B) on which a majority of the members shall be—

(i) individuals with developmental disabilities who are eligible for services, or have received or are receiving services, through the system; or

(ii) parents, family members, guardians, advocates, or authorized representatives of individuals referred to in clause (i).

(b) Legal action

(1) In general

Nothing in this subchapter shall preclude a system from bringing a suit on behalf of individuals with developmental disabilities against a State, or an agency or instrumentality of a State.

(2) Use of amounts from judgment

An amount received pursuant to a suit described in paragraph (1) through a court judgment may only be used by the system to further the purpose of this part and shall not be used to augment payments to legal contractors or to award personal bonuses.

(3) Limitation

The system shall use assistance provided under this part in a manner consistent with section 14404 of this title.

(c) Disclosure of information

For purposes of any periodic audit, report, or evaluation required under this part, the Secretary shall not require an entity carrying out a program to disclose the identity of, or any other personally identifiable information related to, any individual requesting assistance under such program.

(d) Public notice of Federal onsite review

The Secretary shall provide advance public notice of any Federal programmatic or administrative onsite review of a system conducted under this part and solicit public comment on the system through such notice. The Secretary shall prepare an onsite visit report containing the results of such review, which shall be distributed to the Governor of the State and to other interested public and private parties. The comments received in response to the public comment solicitation notice shall be included in the onsite visit report.

(e) Reports

Beginning in fiscal year 2002, each system established in a State pursuant to this part shall annually prepare and transmit to the Secretary a report that describes the activities, accomplishments, and
§ 15045. Authorization of appropriations

For allotments under section 15042 of this title, there are authorized to be appropriated $32,000,000 for fiscal year 2001 and such sums as may be necessary for each of fiscal years 2002 through 2007.

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

§ 15061. Grant authority

(a) National network

From appropriations authorized under section 15066 (a)(1) of this title, the Secretary shall make 5-year grants to entities in each State designated as University Centers for Excellence in Developmental Disabilities Education, Research, and Service to carry out activities described in section 15063 (a) of this title.

(b) National training initiatives

From appropriations authorized under section 15066 (a)(1) of this title and reserved under section 15066 (a)(2) of this title, the Secretary shall make grants to Centers to carry out activities described in section 15063 (b) of this title.

(c) Technical assistance

From appropriations authorized under section 15066 (a)(1) of this title and reserved under section 15066 (a)(3) of this title (or from funds reserved under section 15083 of this title, as appropriate), the Secretary shall enter into 1 or more cooperative agreements or contracts for the purpose of providing technical assistance described in section 15063 (c) of this title.


§ 15062. Grant awards

(a) Existing Centers

(1) In general

In awarding and distributing grant funds under section 15061 (a)of this title for a fiscal year, the Secretary, subject to the availability of appropriations and the condition specified in subsection (d) of this section, shall award and distribute grant funds in equal amounts of $500,000 (adjusted in accordance with subsection (b) of this section), to each Center that existed during the preceding fiscal year and that meets the requirements of this part, prior to making grants under subsection (c) or (d) of this section.

(2) Reduction of award

Notwithstanding paragraph (1), if the aggregate of the funds to be awarded to the Centers pursuant to paragraph (1) for any fiscal year exceeds the total amount appropriated under section 15066 of this title for such fiscal year, the amount to be awarded to each Center for such fiscal year shall be proportionately reduced.

(b) Adjustments

Subject to the availability of appropriations, for any fiscal year following a year in which each Center described in subsection (a) of this section received a grant award of not less than $500,000 under subsection (a) of this section (adjusted in accordance with this subsection), the Secretary shall adjust the awards to take into account the most recent percentage change in the Consumer Price Index published by the Secretary of Labor under section 720 (c)(1) of title 29 (if the percentage change indicates an increase), prior to making grants under subsection (c) or (d) of this section.

(c) National training initiatives on critical and emerging needs

Subject to the availability of appropriations, for any fiscal year in which each Center described in subsection (a) of this section receives a grant award of not less than $500,000, under subsection (a) of
this section (adjusted in accordance with subsection (b) of this section), after making the grant awards, the Secretary shall make grants under section 15061 (b) of this title to Centers to pay for the Federal share of the cost of training initiatives related to the unmet needs of individuals with developmental disabilities and their families, as described in section 15063 (b) of this title.

(d) Additional grants

For any fiscal year in which each Center described in subsection (a) of this section receives a grant award of not less than $500,000 under subsection (a) of this section (adjusted in accordance with subsection (b) of this section), after making the grant awards, the Secretary may make grants under section 15061 (a) of this title for activities described in section 15063 (a) of this title to additional Centers, or additional grants to Centers, 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.


§ 15063. Purpose and scope of activities

(a) National network of University Centers for Excellence in Developmental Disabilities Education, Research, and Service

(1) In general

In order to provide leadership in, advise Federal, State, and community policymakers about, and promote opportunities for individuals with developmental disabilities to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life, the Secretary shall award grants to eligible entities designated as Centers in each State to pay for the Federal share of the cost of the administration and operation of the Centers. The Centers shall be interdisciplinary education, research, and public service units of universities (as defined by the Secretary) or public or not-for-profit entities associated with universities that engage in core functions, described in paragraph (2), addressing, directly or indirectly, 1 or more of the areas of emphasis.

(2) Core functions

The core functions referred to in paragraph (1) shall include the following:

(A) Provision of interdisciplinary pre-service preparation and continuing education of students and fellows, which may include the preparation and continuing education of leadership, direct service, clinical, or other personnel to strengthen and increase the capacity of States and communities to achieve the purpose of this subchapter.

(B) Provision of community services—

(i) that provide training or technical assistance for individuals with developmental disabilities, their families, professionals, paraprofessionals, policymakers, students, and other members of the community; and

(ii) that may provide services, supports, and assistance for the persons described in clause (i) through demonstration and model activities.

(C) Conduct of research, which may include basic or applied research, evaluation, and the analysis of public policy in areas that affect or could affect, either positively or negatively, individuals with developmental disabilities and their families.

(D) Dissemination of information related to activities undertaken to address the purpose of this subchapter, especially dissemination of information that demonstrates that the network
authorized under this part is a national and international resource that includes specific substantive areas of expertise that may be accessed and applied in diverse settings and circumstances.

(b) National training initiatives on critical and emerging needs

(1) Supplemental grants

After consultation with relevant, informed sources, including individuals with developmental disabilities and their families, the Secretary shall award, under section 15061 (b) of this title, supplemental grants to Centers to pay for the Federal share of the cost of training initiatives related to the unmet needs of individuals with developmental disabilities and their families. The Secretary shall make the grants on a competitive basis, and for periods of not more than 5 years.

(2) Establishment of consultation process by the Secretary

Not later than 1 year after October 30, 2000, the Secretary shall establish a consultation process that, on an ongoing basis, allows the Secretary to identify and address, through supplemental grants authorized under paragraph (1), training initiatives related to the unmet needs of individuals with developmental disabilities and their families.

(c) Technical assistance

In order to strengthen and support the national network of Centers, the Secretary may enter into 1 or more cooperative agreements or contracts to—

(1) assist in national and international dissemination of specific information from multiple Centers and, in appropriate cases, other entities whose work affects the lives of individuals with developmental disabilities;

(2) compile, analyze, and disseminate state-of-the-art training, research, and demonstration results policies, and practices from multiple Centers and, in appropriate cases, other entities whose work affects the lives of persons with developmental disabilities;

(3) convene experts from multiple Centers to discuss and make recommendations with regard to national emerging needs of individuals with developmental disabilities;

(4) (A) develop portals that link users with every Center’s website; and

(B) facilitate electronic information sharing using state-of-the-art Internet technologies such as real-time online discussions, multipoint video conferencing, and web-based audio/video broadcasts, on emerging topics that impact individuals with disabilities and their families;

(5) serve as a research-based resource for Federal and State policymakers on information concerning and issues impacting individuals with developmental disabilities and entities that assist or serve those individuals; or

(6) undertake any other functions that the Secretary determines to be appropriate;


to promote the viability and use of the resources and expertise of the Centers nationally and internationally.


§ 15064. Applications

(a) Applications for core Center grants

(1) In general

To be eligible to receive a grant under section 15061 (a) of this title for a Center, an entity shall submit to the Secretary, and obtain approval of, an application at such time, in such manner, and containing such information, as the Secretary may require.

(2) Application contents
Each application described in paragraph (1) shall describe a 5-year plan, including a projected goal related to 1 or more areas of emphasis for each of the core functions described in section 15063 (a) of this title.

(3) Assurances

The application shall be approved by the Secretary only if the application contains or is supported by reasonable assurances that the entity designated as the Center will—

(A) meet regulatory standards as established by the Secretary for Centers;

(B) address the projected goals, and carry out goal-related activities, based on data driven strategic planning and in a manner consistent with the objectives of this part, that—

(i) are developed in collaboration with the consumer advisory committee established pursuant to subparagraph (E);

(ii) are consistent with, and to the extent feasible complement and further, the Council goals contained in the State plan submitted under section 15024 of this title and the system goals established under section 15043 of this title; and

(iii) will be reviewed and revised annually as necessary to address emerging trends and needs;

(C) use the funds made available through the grant to supplement, and not supplant, the funds that would otherwise be made available for activities described in section 15063 (a) of this title;

(D) protect, consistent with the policy specified in section 15001 (c) of this title (relating to rights of individuals with developmental disabilities), the legal and human rights of all individuals with developmental disabilities (especially those individuals under State guardianship) who are involved in activities carried out under programs assisted under this part;

(E) establish a consumer advisory committee—

(i) of which a majority of the members shall be individuals with developmental disabilities and family members of such individuals;

(ii) that is comprised of—

(I) individuals with developmental disabilities and related disabilities;

(II) family members of individuals with developmental disabilities;

(III) a representative of the State protection and advocacy system;

(IV) a representative of the State Council on Developmental Disabilities;

(V) a representative of a self-advocacy organization described in section 15024 (c)(4)(A)(ii)(I) of this title; and

(VI) representatives of organizations that may include parent training and information centers assisted under section 1471 or 1472 of title 20, entities carrying out activities authorized under section 3003 or 3004 of title 29, relevant State agencies, and other community groups concerned with the welfare of individuals with developmental disabilities and their families;

(iii) that reflects the racial and ethnic diversity of the State; and

(iv) that shall—

(I) consult with the Director of the Center regarding the development of the 5-year plan, and shall participate in an annual review of, and comment on, the progress of the Center in meeting the projected goals contained in the plan, and shall make recommendations to the Director of the Center regarding any proposed revisions of the plan that might be necessary; and

(II) meet as often as necessary to carry out the role of the committee, but at a minimum twice during each grant year;
(F) to the extent possible, utilize the infrastructure and resources obtained through funds made available under the grant to leverage additional public and private funds to successfully achieve the projected goals developed in the 5-year plan;

(G) (i) have a director with appropriate academic credentials, demonstrated leadership, expertise regarding developmental disabilities, significant experience in managing grants and contracts, and the ability to leverage public and private funds; and

(ii) allocate adequate staff time to carry out activities related to each of the core functions described in section 15063 (a) of this title; and

(H) educate, and disseminate information related to the purpose of this subchapter to, the legislature of the State in which the Center is located, and to Members of Congress from such State.

(b) Supplemental grant applications pertaining to national training initiatives in critical and emerging needs

To be eligible to receive a supplemental grant under section 15061 (b) of this title, a Center may submit a supplemental application to the Secretary at such time, in such manner, and containing such information as the Secretary may require, pursuant to the terms and conditions set by the Secretary consistent with section 15063 (b) of this title.

(c) Peer review

(1) In general

The Secretary shall require that all applications submitted under this part be subject to technical and qualitative review by peer review groups established under paragraph (2). The Secretary may approve an application under this part only if such application has been recommended by a peer review group that has conducted the peer review required under this paragraph. In conducting the review, the group may conduct onsite visits or inspections of related activities as necessary.

(2) Establishment of peer review groups

   (A) In general

The Secretary, acting through the Commissioner of the Administration on Developmental Disabilities, may, notwithstanding—

   (i) the provisions of title 5 concerning appointments to the competitive service; and

   (ii) the provisions of chapter 51, and subchapter III of chapter 53 of title 5 concerning classification and General Schedule pay rates;

establish such peer review groups and appoint and set the rates of pay of members of such groups.

   (B) Composition

Each peer review group shall include such individuals with disabilities and parents, guardians, or advocates of or for individuals with developmental disabilities, as are necessary to carry out this subsection.

   (3) Waivers of approval

The Secretary may waive the provisions of paragraph (1) with respect to review and approval of an application if the Secretary determines that exceptional circumstances warrant such a waiver.

(d) Federal share

(1) In general

The Federal share of the cost of administration or operation of a Center, or the cost of carrying out a training initiative, supported by a grant made under this part may not be more than 75 percent of the necessary cost of such project, as determined by the Secretary.

(2) Urban or rural poverty areas
In the case of a project whose activities or products target individuals with developmental disabilities who live in an urban or rural poverty area, as determined by the Secretary, the Federal share of the cost of the project may not be more than 90 percent of the necessary costs of the project, as determined by the Secretary.

(3) Grant expenditures

For the purpose of determining the Federal share with respect to the project, expenditures on that project by a political subdivision of a State or by a public or private entity shall, subject to such limitations and conditions as the Secretary may by regulation prescribe under section 15004 (b) of this title, be considered to be expenditures made by a Center under this part.

(e) Annual report

Each Center shall annually prepare and transmit to the Secretary a report containing—

(1) information on progress made in achieving the projected goals of the Center for the previous year, including—

(A) the extent to which the goals were achieved;

(B) a description of the strategies that contributed to achieving the goals;

(C) to the extent to which the goals were not achieved, a description of factors that impeded the achievement; and

(D) an accounting of the manner in which funds paid to the Center under this part for a fiscal year were expended;

(2) information on proposed revisions to the goals; and

(3) a description of successful efforts to leverage funds, other than funds made available under this part, to pursue goals consistent with this part.
From any amount appropriated for a fiscal year under paragraph (1) and remaining after each Center described in section 15062 (a) of this title has received a grant award of not less than $500,000, as described in section 15062 of this title, the Secretary shall reserve funds for the training initiatives authorized under section 15063 (b) of this title.

(3) Reservation for technical assistance

(A) Years before appropriation trigger
For any covered year, the Secretary shall reserve funds in accordance with section 15083 (c) of this title to fund technical assistance activities under section 15063 (c) of this title (other than section 15063 (c)(4) of this title).

(B) Years after appropriation trigger
For any fiscal year that is not a covered year, the Secretary shall reserve not less than $300,000 and not more than 2 percent of the amount appropriated under paragraph (1) to fund technical assistance activities under section 15063 (c) of this title (other than section 15063 (c)(4) of this title).

(C) Covered year
In this paragraph, the term “covered year” means a fiscal year prior to the first fiscal year for which the amount appropriated under paragraph (1) is not less than $20,000,000.

(b) Limitation
The Secretary may not use, for peer review or other activities directly related to peer review conducted under this part—

(1) for fiscal year 2001, more than $300,000 of the funds made available under subsection (a) of this section; and

(2) for any succeeding fiscal year, more than the amount of funds used for the peer review and related activities in fiscal year 2001, adjusted to take into account the most recent percentage change in the Consumer Price Index published by the Secretary of Labor under section 720 (c)(1) of title 29 (if the percentage change indicates an increase).

Part E—Projects of National Significance

§ 15081. Purpose

The purpose of this part is to provide grants, contracts, or cooperative agreements for projects of national significance that—

1. create opportunities for individuals with developmental disabilities to directly and fully contribute to, and participate in, all facets of community life; and
2. support the development of national and State policies that reinforce and promote, with the support of families, guardians, advocates, and communities, of individuals with developmental disabilities, the self-determination, independence, productivity, and integration and inclusion in all facets of community life of such individuals through—
   A. family support activities;
   B. data collection and analysis;
   C. technical assistance to entities funded under parts B and D of this subchapter, subject to the limitations described in sections 15029 (b), 15066 (a)(3), and 15083 (c) of this title; and
   D. other projects of sufficient size and scope that hold promise to expand or improve opportunities for such individuals, including—
      i. projects that provide technical assistance for the development of information and referral systems;
      ii. projects that provide technical assistance to self-advocacy organizations of individuals with developmental disabilities;
      iii. projects that provide education for policymakers;
      iv. Federal interagency initiatives;
      v. projects that enhance the participation of racial and ethnic minorities in public and private sector initiatives in developmental disabilities;
      vi. projects that provide aid to transition youth with developmental disabilities from school to adult life, especially in finding employment and postsecondary education opportunities and in upgrading and changing any assistive technology devices that may be needed as a youth matures;
      vii. initiatives that address the development of community quality assurance systems and the training related to the development, implementation, and evaluation of such systems, including training of individuals with developmental disabilities and their families;
      viii. initiatives that address the needs of aging individuals with developmental disabilities and aging caregivers of adults with developmental disabilities in the community;
      ix. initiatives that create greater access to and use of generic services systems, community organizations, and associations, and initiatives that assist in community economic development;
      x. initiatives that create access to increased living options;
      xi. initiatives that address the challenging behaviors of individuals with developmental disabilities, including initiatives that promote positive alternatives to the use of restraints and seclusion; and
      xii. initiatives that address other areas of emerging need.

§ 15082. Grant authority

(a) In general

The Secretary shall award grants, contracts, or cooperative agreements to public or private nonprofit entities for projects of national significance relating to individuals with developmental disabilities to carry out activities described in section 15081 (2) of this title.

(b) Federal interagency initiatives

(1) In general

(A) Authority

The Secretary may—

(i) enter into agreements with Federal agencies to jointly carry out activities described in section 15081 (2) of this title or to jointly carry out activities of common interest related to the objectives of such section; and

(ii) transfer to such agencies for such purposes funds appropriated under this part, and receive and use funds from such agencies for such purposes.

(B) Relation to program purposes

Funds transferred or received pursuant to this paragraph shall be used only in accordance with statutes authorizing the appropriation of such funds. Such funds shall be made available through grants, contracts, or cooperative agreements only to recipients eligible to receive such funds under such statutes.

(C) Procedures and criteria

If the Secretary enters into an agreement under this subsection for the administration of a jointly funded project—

(i) the agreement shall specify which agency’s procedures shall be used to award grants, contracts, or cooperative agreements and to administer such awards;

(ii) the participating agencies may develop a single set of criteria for the jointly funded project, and may require applicants to submit a single application for joint review by such agencies; and

(iii) unless the heads of the participating agencies develop joint eligibility requirements, an applicant for an award for the project shall meet the eligibility requirements of each program involved.

(2) Limitation

The Secretary may not construe the provisions of this subsection to take precedence over a limitation on joint funding contained in an applicable statute.


§ 15083. Authorization of appropriations

(a) In general

There are authorized to be appropriated to carry out the projects specified in this section $16,000,000 for fiscal year 2001, and such sums as may be necessary for each of fiscal years 2002 through 2007.

(b) Use of funds

(1) Grants, contracts, and agreements
Except as provided in paragraph (2), the amount appropriated under subsection (a) of this section for each fiscal year shall be used to award grants, or enter into contracts, cooperative agreements, or other agreements, under section 15082 of this title.

(2) Administrative costs

Not more than 1 percent of the amount appropriated under subsection (a) of this section for each fiscal year may be used to provide for the administrative costs (other than compensation of Federal employees) of the Administration on Developmental Disabilities for administering this part and parts B, C, and D of this subchapter, including monitoring the performance of and providing technical assistance to, entities that receive funds under this subchapter.

(c) Technical assistance for Councils and Centers

(1) In general

For each covered year, the Secretary shall expend, to provide technical assistance for entities funded under part B or D of this subchapter, an amount from funds appropriated under subsection (a) of this section that is not less than the amount the Secretary expended on technical assistance for entities funded under that part (or a corresponding provision) in the previous fiscal year.

(2) Covered year

In this subsection, the term “covered year” means—

(A) in the case of an expenditure for entities funded under part B of this subchapter, a fiscal year for which the amount appropriated under section 15029 (a) of this title is less than $76,000,000; and

(B) in the case of an expenditure for entities funded under part D of this subchapter, a fiscal year prior to the first fiscal year for which the amount appropriated under section 15066 (a)(1) of this title is not less than $20,000,000.

(3) References

References in this subsection to part D of this subchapter shall not be considered to include section 15063 (c)(4) of this title.

(d) Technical assistance on electronic information sharing

In addition to any funds reserved under subsection (c) of this section, the Secretary shall reserve $100,000 from the amount appropriated under subsection (a) of this section for each fiscal year to carry out section 15063 (c)(4) of this title.

(e) Limitation

For any fiscal year for which the amount appropriated under subsection (a) of this section is not less than $10,000,000, not more than 50 percent of such amount shall be used for activities carried out under section 15081 (2)(A) of this title.

§ 15091. Findings, purposes, and policy

(a) Findings

Congress makes the following findings:

(1) It is in the best interest of our Nation to preserve, strengthen, and maintain the family.

(2) Families of children with disabilities provide support, care, and training to their children that can save States millions of dollars. Without the efforts of family caregivers, many persons with disabilities would receive care through State-supported out-of-home placements.

(3) Most families of children with disabilities, especially families in unserved and underserved populations, do not have access to family-centered and family-directed services to support such families in their efforts to care for such children at home.

(4) Medical advances and improved health care have increased the life span of many people with disabilities, and the combination of the longer life spans and the aging of family caregivers places a continually increasing demand on the finite service delivery systems of the States.

(5) In 1996, 49 States provided family support initiatives in response to the needs of families of children with disabilities. Such initiatives included the provision of cash subsidies, respite care, and other forms of support. There is a need in each State, however, to strengthen, expand, and coordinate the activities of a system of family support services for families of children with disabilities that is easily accessible, avoids duplication, uses resources efficiently, and prevents gaps in services to families in all areas of the State.

(6) The goals of the Nation properly include the goal of providing to families of children with disabilities the family support services necessary—

(A) to support the family;

(B) to enable families of children with disabilities to nurture and enjoy their children at home;

(C) to enable families of children with disabilities to make informed choices and decisions regarding the nature of supports, resources, services, and other assistance made available to such families; and

(D) to support family caregivers of adults with disabilities.

(b) Purposes

The purposes of this subchapter are—

(1) to promote and strengthen the implementation of comprehensive State systems of family support services, for families with children with disabilities, that are family-centered and family-directed, and that provide families with the greatest possible decisionmaking authority and control regarding the nature and use of services and support;

(2) to promote leadership by families in planning, policy development, implementation, and evaluation of family support services for families of children with disabilities;

(3) to promote and develop interagency coordination and collaboration between agencies responsible for providing the services; and

(4) to increase the availability of, funding for, access to, and provision of family support services for families of children with disabilities.

(c) Policy

It is the policy of the United States that all programs, projects, and activities funded under this subchapter shall be family-centered and family-directed, and shall be provided in a manner consistent with the goal of providing families of children with disabilities with the support the families need to raise their children at home.
† 64  †


§ 15092. Definitions and special rule

(a) Definitions

In this subchapter:

(1) Child with a disability

The term “child with a disability” means an individual who—

(A) has a significant physical or mental impairment, as defined pursuant to State policy to the extent that such policy is established without regard to type of disability; or

(B) is an infant or a young child from birth through age 8 and has a substantial developmental delay or specific congenital or acquired condition that presents a high probability of resulting in a disability if services are not provided to the infant or child.

(2) Family

(A) In general

Subject to subparagraph (B), for purposes of the application of this subchapter in a State, the term “family” has the meaning given the term by the State.

(B) Exclusion of employees

The term does not include an employee who, acting in a paid employment capacity, provides services to a child with a disability in an out-of-home setting such as a hospital, nursing home, personal care home, board and care home, group home, or other facility.

(3) Family support for families of children with disabilities

The term “family support for families of children with disabilities” means supports, resources, services, and other assistance provided to families of children with disabilities pursuant to State policy that are designed to—

(A) support families in the efforts of such families to raise their children with disabilities in the home;

(B) strengthen the role of the family as primary caregiver for such children;

(C) prevent involuntary out-of-the-home placement of such children and maintain family unity; and

(D) reunite families with children with disabilities who have been placed out of the home, whenever possible.

(4) Secretary

The term “Secretary” means the Secretary of Health and Human Services.

(5) State

The term “State” means each of the 50 States of the United States, the District of Columbia, the Commonwealth of Puerto Rico, the United States Virgin Islands, Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands.

(6) Systems change activities

The term “systems change activities” means efforts that result in laws, regulations, policies, practices, or organizational structures—
(A) that are family-centered and family-directed;
(B) that facilitate and increase access to, provision of, and funding for, family support services for families of children with disabilities; and
(C) that otherwise accomplish the purposes of this subchapter.

(b) Special rule

References in this subchapter to a child with a disability shall be considered to include references to an individual who is not younger than age 18 who—

(1) has a significant impairment described in subsection (a)(1)(A) of this section; and
(2) is residing with and receiving assistance from a family member.


§ 15093. Grants to States

(a) In general

The Secretary shall make grants to States on a competitive basis, in accordance with the provisions of this subchapter, to support systems change activities designed to assist States to develop and implement, or expand and enhance, a statewide system of family support services for families of children with disabilities that accomplishes the purposes of this subchapter.

(b) Award period and grant limitation

No grant shall be awarded under this section for a period of more than 3 years. No State shall be eligible for more than 1 grant under this section.

(c) Amount of grants

(1) Grants to States

(A) Federal matching share

From amounts appropriated under section 15101 (a) of this title, the Secretary shall pay to each State that has an application approved under section 15094 of this title, for each year of the grant period, an amount that is—

(i) equal to not more than 75 percent of the cost of the systems change activities to be carried out by the State; and

(ii) not less than $100,000 and not more than $500,000.

(B) Non-Federal share

The non-Federal share of the cost of the systems change activities may be in cash or in kind, fairly evaluated, including plant, equipment, or services.

(2) Calculation of amounts

The Secretary shall calculate a grant amount described in paragraph (1) on the basis of—

(A) the amounts available for making grants under this section; and

(B) the child population of the State concerned.

(d) Priority for previously participating States

For the second and third fiscal years for which amounts are appropriated to carry out this section, the Secretary, in providing payments under this section, shall give priority to States that received payments under this section during the preceding fiscal year.

(e) Priorities for distribution

To the extent practicable, the Secretary shall award grants to States under this section in a manner that—

(1) is geographically equitable;
(2) distributes the grants among States that have differing levels of development of statewide systems of family support services for families of children with disabilities; and
(3) distributes the grants among States that attempt to meet the needs of unserved and underserved populations, such as individuals from racial and ethnic minority backgrounds, disadvantaged individuals, individuals with limited English proficiency, and individuals from underserved geographic areas (rural or urban).


§ 15094. Application

To be eligible to receive a grant under this subchapter, a State shall submit an application to the Secretary at such time, in such manner, and containing such information and assurances as the Secretary may require, including information about the designation of a lead entity, a description of available State resources, and assurances that systems change activities will be family-centered and family-directed.


§ 15095. Designation of the lead entity

(a) Designation

The Chief Executive Officer of a State that desires to receive a grant under section 15093 of this title, shall designate the office or entity (referred to in this subchapter as the “lead entity”) responsible for—
(1) submitting the application described in section 15094 of this title on behalf of the State;
(2) administering and supervising the use of the amounts made available under the grant;
(3) coordinating efforts related to and supervising the preparation of the application;
(4) coordinating the planning, development, implementation (or expansion and enhancement), and evaluation of a statewide system of family support services for families of children with disabilities among public agencies and between public agencies and private agencies, including coordinating efforts related to entering into interagency agreements;
(5) coordinating efforts related to the participation by families of children with disabilities in activities carried out under a grant made under this subchapter; and
(6) submitting the report described in section 15097 of this title on behalf of the State.

(b) Qualifications

In designating the lead entity, the Chief Executive Officer may designate—
(1) an office of the Chief Executive Officer;
(2) a commission appointed by the Chief Executive Officer;
(3) a public agency;
(4) a council established under Federal or State law; or
(5) another appropriate office, agency, or entity.


§ 15096. Authorized activities

(a) In general
A State that receives a grant under section 15093 of this title shall use the funds made available through the grant to carry out systems change activities that accomplish the purposes of this subchapter.

(b) **Special rule**

In carrying out activities authorized under this subchapter, a State shall ensure that such activities address the needs of families of children with disabilities from unserved or underserved populations.


§ 15097. Reporting

A State that receives a grant under this subchapter shall prepare and submit to the Secretary, at the end of the grant period, a report containing the results of State efforts to develop and implement, or expand and enhance, a statewide system of family support services for families of children with disabilities.


§ 15098. Technical assistance

(a) **In general**

The Secretary shall enter into contracts or cooperative agreements with appropriate public or private agencies and organizations, including institutions of higher education, with documented experience, expertise, and capacity, for the purpose of providing technical assistance and information with respect to the development and implementation, or expansion and enhancement, of a statewide system of family support services for families of children with disabilities.

(b) **Purpose**

An agency or organization that provides technical assistance and information under this section in a State that receives a grant under this subchapter shall provide the technical assistance and information to the lead entity of the State, family members of children with disabilities, organizations, service providers, and policymakers involved with children with disabilities and their families. Such an agency or organization may also provide technical assistance and information to a State that does not receive a grant under this subchapter.

(c) **Reports to the Secretary**

An entity providing technical assistance and information under this section shall prepare and submit to the Secretary periodic reports regarding Federal policies and procedures identified within the States that facilitate or impede the delivery of family support services to families of children with disabilities. The report shall include recommendations to the Secretary regarding the delivery of services, coordination with other programs, and integration of the policies described in section 15091 of this title in Federal law, other than this subchapter.


§ 15099. Evaluation

(a) **In general**

The Secretary shall conduct a national evaluation of the program of grants to States authorized by this subchapter.

(b) **Purpose**

(1) **In general**
The Secretary shall conduct the evaluation under subsection (a) of this section to assess the status and effects of State efforts to develop and implement, or expand and enhance, statewide systems of family support services for families of children with disabilities in a manner consistent with the provisions of this subchapter. In particular, the Secretary shall assess the impact of such efforts on families of children with disabilities, and recommend amendments to this subchapter that are necessary to assist States to accomplish fully the purposes of this subchapter.

(2) Information systems

The Secretary shall work with the States to develop an information system designed to compile and report, from information provided by the States, qualitative and quantitative descriptions of the impact of the program of grants to States authorized by this subchapter on—

(A) families of children with disabilities, including families from unserved and underserved populations;

(B) access to and funding for family support services for families of children with disabilities;

(C) interagency coordination and collaboration between agencies responsible for providing the services; and

(D) the involvement of families of children with disabilities at all levels of the statewide systems.

(c) Report to Congress

Not later than 2 1/2 years after October 30, 2000, the Secretary shall prepare and submit to the appropriate committees of Congress a report concerning the results of the evaluation conducted under this section.


§ 15100. Projects of national significance

(a) Study by the Secretary

The Secretary shall review Federal programs to determine the extent to which such programs facilitate or impede access to, provision of, and funding for family support services for families of children with disabilities, consistent with the policies described in section 15091 of this title.

(b) Projects of national significance

The Secretary shall make grants or enter into contracts for projects of national significance to support the development of national and State policies and practices related to the development and implementation, or expansion and enhancement, of family-centered and family-directed systems of family support services for families of children with disabilities.


§ 15101. Authorization of appropriations

(a) In general

There are authorized to be appropriated to carry out this subchapter such sums as may be necessary for each of fiscal years 2001 through 2007.

(b) Reservation

(1) In general

The Secretary shall reserve for each fiscal year 10 percent, or $400,000 (whichever is greater), of the amount appropriated pursuant to subsection (a) of this section to carry out—

(A) section 15098 of this title (relating to the provision of technical assistance and information to States); and

(B) section 15099 of this title (relating to the conduct of evaluations).

(2) Special rule

For each year that the amount appropriated pursuant to subsection (a) of this section is $10,000,000 or greater, the Secretary may reserve 5 percent of such amount to carry out section 15100 of this title.

§ 15111. Findings

Congress finds that—

(1) direct support workers, especially young adults, have played essential roles in providing the support needed by individuals with developmental disabilities and expanding community options for those individuals;

(2) 4 factors have contributed to a decrease in the available pool of direct support workers, specifically—

  (A) the small population of individuals who are age 18 through 25, an age group that has been attracted to direct support work in the past;
  (B) the rapid expansion of the service sector, which attracts individuals who previously would have elected to pursue employment as direct support workers;
  (C) the failure of wages in the human services sector to keep pace with wages in other service sectors; and
  (D) the lack of quality training and career advancement opportunities available to direct support workers; and

(3) individuals with developmental disabilities benefit from assistance from direct support workers who are well trained, and benefit from receiving services from professionals who have spent time as direct support workers.


§ 15112. Definitions

In this subchapter:

(1) Developmental disability

The term “developmental disability” has the meaning given the term in section 15002 of this title.

(2) Institution of higher education

The term “institution of higher education” has the meaning given the term in section 1141 1 of title 20.

(3) Secretary

The term “Secretary” means the Secretary of Health and Human Services.

Footnotes

1 See References in Text note below.


References in Text

Section 1141 of title 20, referred to in par. (2), was repealed by Pub. L. 105–244, § 3, title I, § 101(b), title VII, § 702, Oct. 7, 1998, 112 Stat. 1585, 1616, 1803, effective Oct. 1, 1998. However, the term “institution of higher education” is defined in section 1001 of Title 20, Education.

§ 15113. Reaching up scholarship program

(a) Program authorization
The Secretary may award grants to eligible entities, on a competitive basis, to enable the entities to carry out scholarship programs by providing vouchers for postsecondary education to direct support workers who assist individuals with developmental disabilities residing in diverse settings. The Secretary shall award the grants to pay for the Federal share of the cost of providing the vouchers.

(b) Eligible entity

To be eligible to receive a grant under this section, an entity shall be—

(1) an institution of higher education;
(2) a State agency; or
(3) a consortium of such institutions or agencies.

(c) Application requirements

To be eligible to receive a grant under this section, an eligible entity shall submit to the Secretary an application at such time, in such manner, and containing such information as the Secretary may require, including a description of—

(1) the basis for awarding the vouchers;
(2) the number of individuals to receive the vouchers; and
(3) the amount of funds that will be made available by the eligible entity to pay for the non-Federal share of the cost of providing the vouchers.

(d) Selection criteria

In awarding a grant under this section for a scholarship program, the Secretary shall give priority to an entity submitting an application that—

(1) specifies that individuals who receive vouchers through the program will be individuals—
   (A) who are direct support workers who assist individuals with developmental disabilities residing in diverse settings, while pursuing postsecondary education; and
   (B) each of whom verifies, prior to receiving the voucher, that the worker has completed 250 hours as a direct support worker in the past 90 days;
(2) states that the vouchers that will be provided through the program will be in amounts of not more than $2,000 per year;
(3) provides an assurance that the eligible entity (or another specified entity that is not a voucher recipient) will contribute the non-Federal share of the cost of providing the vouchers; and
(4) meets such other conditions as the Secretary may specify.

(e) Federal share

The Federal share of the cost of providing the vouchers shall be not more than 80 percent.


§ 15114. Staff development curriculum authorization

(a) Funding

(1) In general

The Secretary shall award funding, on a competitive basis, through a grant, cooperative agreement, or contract, to a public or private entity or a combination of such entities, for the development, evaluation, and dissemination of a staff development curriculum, and related guidelines, for computer-assisted, competency-based, multimedia, interactive instruction, relating to service as a direct support worker.

(2) Participants

The curriculum shall be developed for individuals who—
(A) seek to become direct support workers who assist individuals with developmental disabilities or are such direct support workers; and

(B) seek to upgrade their skills and competencies related to being a direct support worker.

(b) Application requirements

To be eligible to receive an award under this section, an entity shall submit to the Secretary an application at such time, in such manner, and containing such information as the Secretary may require, including—

(1) a comprehensive analysis of the content of direct support roles;

(2) information identifying an advisory group that—

(A) is comprised of individuals with experience and expertise with regard to the support provided by direct support workers, and effective ways to provide the support, for individuals with developmental disabilities in diverse settings; and

(B) will advise the entity throughout the development, evaluation, and dissemination of the staff development curriculum and guidelines;

(3) information describing how the entity will—

(A) develop, field test, and validate a staff development curriculum that—

(i) relates to the appropriate reading level for direct service workers who assist individuals with disabilities;

(ii) allows for multiple levels of instruction;

(iii) provides instruction appropriate for direct support workers who work in diverse settings; and

(iv) is consistent with subsections (b) and (c) of section 15001 of this title and section 15009 of this title;

(B) develop, field test, and validate guidelines for the organizations that use the curriculum that provide for—

(i) providing necessary technical and instructional support to trainers and mentors for the participants;

(ii) ensuring easy access to and use of such curriculum by workers that choose to participate in using, and agencies that choose to use, the curriculum;

(iii) evaluating the proficiency of the participants with respect to the content of the curriculum;

(iv) providing necessary support to the participants to assure that the participants have access to, and proficiency in using, a computer in order to participate in the development, testing, and validation process;

(v) providing necessary technical and instructional support to trainers and mentors for the participants in conjunction with the development, testing, and validation process;

(vi) addressing the satisfaction of participants, individuals with developmental disabilities and their families, providers of services for such individuals and families, and other relevant entities with the curriculum; and

(vii) developing methods to maintain a record of the instruction completed, and the content mastered, by each participant under the curriculum; and

(C) nationally disseminate the curriculum and guidelines, including dissemination through—

(i) parent training and information centers funded under part D of the Individuals with Disabilities Education Act (20 U.S.C. 1451 et seq.);

(ii) community-based organizations of and for individuals with developmental disabilities and their families;

(iii) entities funded under subchapter I of this chapter;
(iv) centers for independent living;
(v) State educational agencies and local educational agencies;
(vi) entities operating appropriate medical facilities;
(vii) postsecondary education entities; and
(viii) other appropriate entities; and

(4) such other information as the Secretary may require.


References in Text
The Individuals with Disabilities Education Act, referred to in subsec. (b)(3)(C)(i), is title VI of Pub. L. 91–230, Apr. 13, 1970, 84 Stat. 175, as amended. Part D of the Act is classified generally to subchapter IV (§ 1450 et seq.) of chapter 33 of Title 20, Education. For complete classification of this Act to the Code, see section 1400 of Title 20 and Tables.

§ 15115. Authorization of appropriations

(a) Scholarships

There are authorized to be appropriated to carry out section 15113 of this title $800,000 for fiscal year 2001 and such sums as may be necessary for each of fiscal years 2002 through 2007.

(b) Staff development curriculum

There are authorized to be appropriated to carry out section 15114 of this title $800,000 for fiscal year 2001 and such sums as may be necessary for each of fiscal years 2002 and 2003.