



Note: This document contains acronyms. DD = developmental disability.

## **VALUES OF THE DD ACT**

The DD Act is a federal law in the United States. It aims to improve service systems for people with DD and their families.

People with DD are supported to access:

- 1) community services
- 2) tailored supports
- 3) other forms of assistance.

Core values and principles in the DD Act include:

### **Independence:**

People with DD have control and choice over their own lives. This means deciding where they live, who they live with, and how they spend their time.

### **Productivity:**

People with DD add to society through:

- 1) income producing jobs
- 2) volunteer jobs
- 3) other actions which add to a household or community.

### **Integration:**

People with DD have equal rights, access and use the same community resources used by other people.

[This information is intended for everyone. Reading ease level: 6.8.](#)

The information in this document was developed as part of a Training and Technical Assistance contract from the Administration on Intellectual and Developmental Disabilities, Contract #75P00121C00067



**Inclusion:**

People with DD participate in all aspects of community life (school, work, and social activities).

**Self-determination:**

People with DD make decisions and choices about their own lives and have supports and services to do so.

**Protection:**

People with DD are safe from abuse, neglect, and being taken advantage of.

**Advocacy:**

People with DD have support to speak up to access needed supports and services.

**Quality of Life:** People with DD have access to healthcare, education, housing, and other basic services.

These core values guide the programs funded by the DD Act.

DD Act funded programs include:

- 1) DD Councils
- 2) Disability Rights
- 3) University Centers

These programs promote the rights and well-being of people with DD.

[This information is intended for everyone. Reading ease level: 6.8.](#)

The information in this document was developed as part of a Training and Technical Assistance contract from the Administration on Intellectual and Developmental Disabilities, Contract #75P00121C00067

# The DD Act

## Part B

### Federal Assistance to State Councils on Developmental Disabilities

An Accessible Format and Plain Language Notes

## Foreword

This publication is an accessible version of the Developmental Disabilities Assistance and Bill of Rights Act (the DD Act) of 2000 Part B: Federal Assistance to State Councils on Developmental Disabilities. This document does not include the general provisions or definitions of the DD Act. The content has not been changed. The format has been updated for accessibility reading. Additional comments have been added for clarity using plain language and from technical assistance discussions. It is a publication of the staff at the Kentucky Commonwealth Council on Developmental Disabilities, December 2021.

[Click this Link for the full US Code DD Act](#)

You can also use your phone with this QR Code:



# Overview

The DD Act is a law that says people with developmental disabilities (DD) and their families have a right to be in their communities living good lives like everybody else. It has 3 titles:

- Title 1- Programs for individuals with developmental disabilities
- Title 2- Family Support
- Title 3- Program for Direct Support Workers who assist people with developmental disabilities

In Title 1, there are 5 areas (subtitles):

- A.** General Provisions
- B.** Federal Assistance to State Councils on Developmental Disabilities
- C.** Protection and Advocacy of Individual Rights
- D.** National Network of University Centers for Excellence in Developmental Disabilities Education, Research and Service
- E.** Projects of National Significance

The DD Act was written to make service systems better for people. It makes sure that people with DD and their families are included in making decisions.

The DD Act includes rules that programs must follow, including Developmental Disability Councils.

There are many parts to the DD Act. This paper focuses on Part B about DD Councils.

# United States Code

## 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 B—Federal Assistance to State Councils on Developmental Disabilities**

<b>Section</b>	<b>US Code</b>
121 Purpose.	15021
122 State allotments.	15022
123 Payments to the States for planning, administration, and services	15023
124 State plan	15024
125 State Councils on Developmental Disabilities and designated state agencies	15025
126 Federal and non-Federal share	15026
127 Withholding of payments for planning, administration, and services	15027
128 Appeals by States	15028
129 Authorization of appropriations.	15029



# Part B—Federal Assistance to State Councils on Developmental Disabilities



**This explains what a council is for.**

## **Section 121 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.



**This explains why each state gets a different amount of grant money.**

## **Section 122 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**

- (i) Except as provided in paragraph (4), for any fiscal year the allotment under this section—
- (ii) 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
- (iii) 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**

- (i) 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**

- (i) 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—
- (ii) 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
- (iii) 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**

- (i) 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**

- (A) 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 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 reallot the amount.

**(2) Timing**

The Secretary may make such a reallotment 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 reallotment in the Federal Register.

**(3) Amounts**

The Secretary shall reallot the amount to other States with respect to which the Secretary has not made that determination. The Secretary shall reallot 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) Reallotment of Reductions**

The Secretary shall similarly reallot 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) for such fiscal year.



**This is about how states get the grant money.**

**Section 123      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.



**This is about the 5 - year state plan each council must do. It explains what must be in the plan.**

**Section 124      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) 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



**The activities a council does must be under an area of emphasis. Areas of emphasis are explained below.**

- (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, 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



**This explains that Councils must have certain goals in their plan.**

- (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  $\frac{1}{2}$  (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 restrictions**

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 assurances**

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) 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.



**This is about council membership and designated state agencies.**

## **Section 125      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).

### **(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.



### **This explains that people with DD and their families must have the highest number of membership on the council.**

- (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.



### **This explains that councils must have state agency representatives**

- (4) Representation of agencies and organizations**
  - (A) In general** Each Council shall include-
    - (i)** representatives of relevant State entities, including
      - (I)** State entities that administer funds provided under Federal laws related to individuals with disabilities, including the Rehabilitation Act of 1973 (29 U.S.C. 701 et seq.), the Individuals with Disabilities Education Act (20 U.S.C. 1400 et seq.), the Older Americans Act of 1965 (42 U.S.C. 3001 et seq.), and titles V and XIX of the Social Security Act (42 U.S.C. 701 et seq. and 1396 et seq.);
      - (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.



## This explains what councils must do.

**(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**

- (A)** At the end of each grant year, each Council shall
- (B)** determine the extent to which each goal of the Council was achieved for that year;
- (C)** determine to the extent that each goal was not achieved, the factors that impeded the achievement;
- (D)** determine needs that require amendment of the 5-year strategic State plan required under section 15024 of this title;
- (E)** separately determine the information on the self-advocacy goal described in section 15024(c)(4)(A)(ii) of this title; and
- (F)** 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.



**Below are ways a council may meet their plan goals. They are called “sanctioned activities.”**

**(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 <sup>1</sup> 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.



**This explains that councils must report each year to show what they have done with their grant money.**

**(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.



## This explains that councils must have a budget with certain items.

### (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.



## **This explains the rules for council staff.**

### **(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.).



## **Most councils will need another state agency to help them with state operations. This is called a designated state agency or DSA.**

### **(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.



## **This explains what a designated state agency does for the Council.**

### **(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.



**This explains how grant money is split into state parts and federal parts.**

**Section 126 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 be not 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.



**This explains how councils can lose grant money if they do not follow federal rules.**

### **Section 127 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.



**This explains how a state can disagree with actions made by the Secretary of the Federal Health and Human Services office.**

### **Section 128 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.



**This explains how the money Congress gives to councils may be used for technical assistance for some of its' work.**

**Section 129 Authorization of appropriations**

**(a) Funding for State allotments**

Except as described in subsection (b), 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) 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) 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) to provide technical assistance to entities funded under this part.