

## **Protection and Advocacy for Individuals with Developmental Disabilities (PADD)**

*42 USC §§ 15041-15045*

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 C-- Protection and Advocacy of Individual Rights

### **42 USC § 15041-- Purpose**

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

### **42 USC § 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 reallocations of such sums shall be made on the same basis as the allotments and reallocations 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 subtitle (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 subtitle 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 subtitle 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.

#### **42 USC § 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 subtitle;
- (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 subtitle, 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 subtitle 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 subtitle, 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.

#### **42 USC §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 title 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 subtitle 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 expenditures of the system during the preceding fiscal year, including a description of the system's goals, the extent to which the goals were achieved, barriers to their achievement, the process used to obtain public input, the nature of such input, and how such input was used.

#### **42 USC §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.