

**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**

**§ 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<sup>1</sup> (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—

*NB: This unofficial compilation of the U.S. Code is current as of Jan. 4, 2012 (see <http://www.law.cornell.edu/uscode/uscpri.html>).*

- (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**

<sup>1</sup> See References in Text note below.

(Pub. L. 106–402, title I, § 143, Oct. 30, 2000, 114 Stat. 1714; Pub. L. 108–364, § 3(a)(3), Oct. 25, 2004, 118 Stat. 1736.)

**References in Text**

The Rehabilitation Act of 1973, referred to in subsec. (a)(2)(D)(ii), is Pub. L. 93–112, Sept. 26, 1973, 87 Stat. 355, as amended, which is classified generally to chapter 16 (§ 701 et seq.) of Title 29, Labor. For complete classification of this Act to the Code, see Short Title note set out under section 701 of Title 29 and Tables.

The Older Americans Act of 1965, referred to in subsec. (a)(2)(D)(ii), is Pub. L. 89–73, July 14, 1965, 79 Stat. 218, as amended, which is classified generally to chapter 35 (§ 3001 et seq.) of this title. For complete classification of this Act to the Code, see Short Title note set out under section 3001 of this title and Tables.

The Protection and Advocacy for Mentally Ill Individuals Act of 1986, referred to in subsec. (a)(2)(D)(ii), was Pub. L. 99–319, May 23, 1986, 100 Stat. 478, as amended. Pub. L. 99–319 was renamed the Protection and Advocacy for Individuals with Mental Illness Act by Pub. L. 106–310, div. B, title XXXII, § 3206(a), Oct. 17, 2000, 114 Stat. 1193, and is classified generally to chapter 114 (§ 10801 et seq.) of this title. For complete classification of this Act to the Code, see Short Title note set out under section 10801 of this title and Tables.

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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**

2004—Subsec. (a)(2)(D)(ii). Pub. L. 108–364 substituted “section 3003 or 3004 of title 29” for “section 3011 or 3012 of title 29”.